



**Facebook for parents of a child with autism spectrum disorder in Malaysia**

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### Abstract

This study explored the use of Facebook for support group for parents of a child with autism spectrum disorder (ASD) in Malaysia. As the number of children being diagnosed with ASD increases every year, worldwide, parents in Malaysia initiated a Facebook support group called Autisme Malaysia to cater to their social support needs. Earlier research investigated the use of online support groups in many Western countries and in a very limited way in Asian countries. With the rise of Facebook as a popular social network site, it is paramount to explore its usage for support group.

This netnography exploratory research aimed to: 1) explore experiences of parents of children with ASD in Malaysia participating in Autisme Malaysia (AM) Facebook group, and 2) investigate the impact of online engagement in this support group on these parents. These participants were parents/members of Autisme Malaysia Facebook group coming from all parts of Malaysia, and involved both mothers and fathers. This research utilised a qualitative approach adopting participant observation, archived Facebook data and semi-structured interviews for data triangulation methods. The participant observation was counted for frequency of activities carried out on Autisme Malaysia, while the other two methods were coded and analysed for pre-empted and emerging themes.

Findings highlighted three major themes: 1) online engagement, 2) social support, and 3) expression of feelings. These three themes were interconnected and illustrated the way in which online communication can provide a culturally and emotionally safe 'space' for sharing challenging personal information. The parents reported positive and negative experiences of their involvement in the group. A major finding of this project is that many parents developed creative and individualised ways to overcome negative experiences to the

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point that they felt that the negative experiences were a manageable part of the lived experience of participating in the group.

*Keywords:* Facebook, support group, parents, child, autism spectrum disorder

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Keywords

**Autism Spectrum Disorder (ASD):** A neurological disorder which affects brain functions typically associated with impairment in communication and socialization, restricted and repetitive interests, movements and activities.

**Autisme Malaysia (AM):** A non-governmental organisation specifically set-up by parents of children with ASD in Malaysia.

**Social support group:** A group set-up specifically to offer social support (emotional, informational, tangible) to patients or parents/carers either formally (health professionals) or informally (patients or parent/carers themselves).

**Facebook:** A social network site dedicated to connecting people despite their geographical location.

**Facebook page:** A personal Facebook page which a Facebook user has set-up to allow him/her to connect with other Facebook users or join a Facebook group.

**Facebook group:** A group which is set-up by an individual specifically for different purposes for users to share similar hobbies or interests, in which the privacy of the group can be set to Closed or Open.

**Private messaging (pm):** A feature in Facebook which allows for synchronous communication to take place between its users, almost similar to chatting function.

**Friend on Facebook:** When users of Facebook are connected to each other, which allows them to utilise all features on Facebook especially Comment. Users who are not *friend* have limited activity, especially viewing the other's status.

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**Status (es):** A post which could comprise text, video or audio which Facebook users post on their Facebook wall, sharing things they do or what they are thinking of. The privacy of a status could be set to be viewed by friends only or public.

**Like:** A non-linguistic feature on Facebook which users can click to indicate they like the status on the wall or the comments made by others or their own.

**Comment (s):** A linguistic feature on Facebook which allows users to write a textual comment or post a video or an audio on other users' status.

**Share:** A non-linguistic feature on Facebook which allows users to share others' status on their own Facebook wall.

**Tag/Tagging:** Involves tagging the name of other Facebook users on the status or comment thread with the purpose of allowing the users (the one being tagged) to view the status/comment (in which they may have missed to read them).

**Administrator (admin):** A person who initiated a Facebook group whose function includes managing the Facebook group, monitoring and controlling the activities conducted by members of the Facebook group.

**Otai:** A nickname given to members who have been in the Autisme Malaysia Facebook group for three years and more and considered as resourceful and point of reference for matters regarding ASD in Malaysia.

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# CHAPTER 1: INTRODUCTION

## 1.0 Introduction

Support groups are the common term used to describe either self-help support groups or professionally operated support groups. According to the Surgeon General Workshop (1988), these two have a clear distinction as the former refers to:

Self-governing groups whose members share a common health concern and give each other emotional support and material aid, charge either no fee or only a small fee for membership, and place high value on experiential knowledge in the belief that it provides a special understanding of a situation. In addition to providing mutual support for their members, such groups may also be involved in giving information, education, material aid, and social advocacy in their communities. (p.5)

The first and most successful self-help group is Alcoholics Anonymous (AA), founded in 1935 by two recovering alcoholics to “help hopeless alcoholics recover from alcoholism, something the medical profession had been unable to do” (Oka & Borkman, 2000, p. 718). This is different from professionally operated support groups which are facilitated and controlled by professionals who most often do not share the problem of the members and often organised in institutional settings, including hospitals and rehabilitation centres (VandenBos, 2007). The American Cancer Society (Hermann, 2001) defines support group as a group of people with common experiences or concerns who provide each other with encouragement, comfort, and advice, which is a definition adopted in this study. Support groups for parents of children with disabilities have been organised mostly by the parents themselves to gain emotional, informational and tangible support. Many researchers have investigated the efficacy of support groups for these parents (Bull, 2003; Douma,



Dekker, & Koot, 2006; MacIntosh, Myers, & Goin-Kochel, 2005; Solomon, Pistrang, & Barker, 2001) which yielded positive responses to support groups. However, distance, time and convenience of needing to provide childcare for their child with a disability may limit these parents to join support groups. Thus, online support groups could resolve this challenge, but very few studies have investigated online support groups for parents of a child with autism spectrum disorder (ASD) (Alat, 2006; Carter, 2009; Clifford, 2011; Huws, Jones, & Ingledew, 2001). Many of these previous studies were set in Western countries involving Caucasians, Hispanics and African-Americans as samples. Limited studies were conducted in Asian settings such as Japan and Korea, and very few in Malaysia (Toran, Yunus, Mohd Yasin, & Wan Md Zain, 2013). It is hoped that this project will contribute to a greater understanding of the role of support groups in a South East Asian context.

Many of the online platforms used for support groups utilise e-mails, chat rooms and bulletin boards. Most online support groups used one of these platforms as a means of communication or a combination of the three. A social network site, such as Facebook, utilises communication features similar to a chat room and bulletin board. At the start of this study in May 2013, there were limited studies looking into the use of Facebook as a platform for online support groups. Many of these past studies have investigated health-related diseases or symptoms such as breast cancer (Bender, Jimenez-Marroquin, & Jadad, 2011), pre-term infants (Thoren, Metze, Bühner, & Garten, 2013) and diabetes (Greene, Choudhry, Kilabuk, & Shrank, 2011), eating disorder (Haas, Irr, Jennings, & Wegner, 2011), depression (Kevin et al., 2013) education (Woodley & Meredith, 2012), and disaster (Taylor, Wells, Howell, & Raphael, 2012). However, there was almost no study investigating the use of Facebook for a support group for parents of a child with ASD. The increased popularity and the number of active users of this social network sites indicate the possibility of it becoming an effective communication tool for support groups for these parents. Facebook offers communicative features, both synchronous and asynchronous, which allows users to

interact wherever they are with 24/7 accessibility. The linguistic and paralinguistic features of Facebook can be utilised as a method for the exchange of social support to occur on the Facebook *wall* or the private messages. For this purpose, the present study sought to qualitatively examine the use of Facebook as a communication tool for social support groups for parents of a child with autism spectrum disorder in Malaysia.

### 1.1 Background to the study

Parenting a child with a disability often presents complex challenges for parents. Parents of a child with autism spectrum disorder (ASD) are believed to experience greater stress compared to parents of a child with other disabilities (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Sivberg, 2002). Statistics indicate that one in every 68 children are affected by ASD worldwide (AutismSpeaks, 2016) and Jones, West, and Stevens (2006) they may exhibit “impairment in communication and socialisation, restricted and repetitive interests, movements and activities” (p. 97). Due to the many conditions in the broad spectrum of ASD, children with ASD might be diagnosed with learning difficulties, epilepsy, speech and language problems, attention deficit hyperactivity disorder (ADHD), developmental coordination disorder, tics and Tourette syndrome and feeding and eating problems. As a result, there is no single definitive approach that could be used to assist parents when dealing with a child with ASD. Accordingly, these parents often experience higher level of stress in comparison with parents of a child with other disabilities such as Down Syndrome, Fragile X, cerebral palsy and developmental delay (Abbeduto et al., 2004; Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009). Therefore, being in a support group may alleviate some of the stress associated with parenting a child with ASD.

Support groups are the avenues by which parents of a child with ASD can get together, share their experiences and obtain and give support to each other. With the

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accessibility of the internet, online support groups have become popular as they can help resolve the issue of distance, time and place for these parents. In contrast, face-to-face support groups pose difficulties for these parents especially when they have to leave their child with ASD with a baby sitter in order to attend the support groups. Thus, the accessibility and 24-hour availability of online support groups from home are the viable options and they have been widely utilised to replace or complement face-to-face support groups. The online platform started with the use of e-mails to chat rooms and to bulletin boards. Facebook seems to capture all these features and since the introduction of Facebook in 2006 (boyd & Ellison, 2008) to everyone in the whole world, it has been utilised for all purposes, from connecting friends, communicating colleagues, teaching and learning, to marketing and businesses. With the myriad of users and uses, Facebook has the potential of maintaining its presence as a well-received social network site for a long period of time. With the increased popularity of Facebook in Malaysia, parents of a child with ASD have started to use this platform for support groups.

### **1.2 Statement of the problem**

The United Nations estimates that an average of 10% of a developing country's population lives with a disability (United Nations, 2006). Statistics by Unicef Malaysia showed that there were 29,289 children with disabilities registered in 2012 in Malaysia and 19,150 from the total were having learning disabilities (Unicef, 2014). The number includes children below 6 to 18 years old. However, in 2011 there was only 10,364 children with learning difficulties within the same age group (Department of Social Welfare, 2013). Hence, there was an increase of 8,786 children who registered with the Social Welfare Department in Malaysia. This huge increase could be due to parents becoming more aware of the importance of registering with the welfare department or more children were indeed diagnosed with learning disabilities. However, in 2012 it was recorded that only 1% of the

total number of children with disabilities in Malaysia were enrolled in suitable special education programmes (Department of Social Welfare, 2013). This figure is likely to be an underestimate of the number of children in the country who actually have special needs as parents of these children may have yet to register their children with the department. In Malaysia, students with special needs include students with visual impairment, hearing impairment, speech difficulties, physical disabilities, multiple disabilities and learning disabilities such as autism, Down's Syndrome, attention deficit hyperactivity disorder (ADHD) and dyslexia (Unicef, 2014).

As the number of children diagnosed with having disabilities/special needs increases, it is pivotal to look into how parents provide the best possible support for these children. Parents of a child with disabilities are often faced and experienced with more parenting stress than parents of typically developing children (Floyd & Gallagher, 1997; Hastings, 2003). Research shows that parents of a child with autism spectrum disorders (ASD) experienced more parenting stress and mental health problems than parents of a child with other disabilities (Blacher & McIntyre, 2006; Eisenhower et al., 2005). This shows that a child with ASD presents more challenges for the parents/carers in comparison to a child with other types of disabilities. Participation in a support group has proven to alleviate stress and provide a sense of belonging for parents of these children (Kerr & McIntosh, 2000; Preyde & Ardal, 2003 ; Singer et al., 1999).

Support groups (especially face-to-face) are relatively cost-effective and easily-implemented intervention that can cater and support the needs of these families (Smith, Gabard, Dale, & Drucker, 1994). Distance, time and place, however, may limit parents' participation in a face-to-face support group which is normally organised by parents of a child with similar disabilities. Thus, an online support group could be one of the solutions for these parents to get social support. Quite a number of studies (Alat, 2006; Carter, 2009; Huws et al., 2001; Reinke & Solheim, 2015) have been conducted to investigate the benefits

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of online support groups for parents of a child with ASD, but till now, very few have looked into Asian parents, in particular parents of a child with ASD in Malaysia. These past researches often looked into the use of e-mails, chat rooms or bulletin boards as the platform for the online support groups, and very few studies (Mustafa, Short, & Fan, 2015; Roffeei, Abdullah, & Basar, 2015) investigated the use of Facebook as a platform for online support groups for parents of a child with ASD.

### **1.3 An overview of Autisme Malaysia Facebook (AM FB) support group**

Facebook had recorded an increasing phenomenal popularity worldwide. As of June 2016, there were 1.13 billion active users with 84.5% of users outside the US and Canada (newsroom, 2016). Within the same time frame, Malaysia documented 19 million active users of Facebook (internetworldstats) and a Facebook group page called Autisme Malaysia (AM) attracted 29,292 members with more users joining in as members each day (Figure 1.1). This Facebook group page was initiated as an online support group for parents of a child with ASD in Malaysia.

When Autisme Malaysia Facebook social support group was initiated back in 2010, it started with only four families. The person who started this Facebook social support group was Mr. Zamri Tembol. Facebook is designed in such a way that a person who started a group automatically becomes the administrator of the group (commonly known as the admin). The role of the admin is to manage the group, monitor the activities conducted in the group which are visible to the admin and moderate the communication that takes place (on the Facebook *wall*). Parents of a child with ASD who wish to join the group have to wait for the approval from the admin before they can join and participate in the Facebook group activities. They can either ask to join or be invited by others who are already a member of the Facebook group (AM). The group started off as a Closed Group, in which whenever members post a status or comment or click on the buttons of Like or Share, it will remain

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visible to its group members only. None of these activities will appear on the members' own timeline on their personal Facebook page. After 2 years, the admin decided to change the setting to Public Group. This allows AM FB support group to become visible to other users of Facebook who are not members of the group. However, this does not allow them to post to the AM FB *wall*. They can only view and read the statuses and comments. This change of privacy setting, however, affected the group's members as the statuses posted by them or other members to the AM FB *wall* will appear on their personal Facebook page timeline.

Since September 2016, the number of parents joining AM FB support group has been increasing. Monitoring the communication has proven to be overwhelming for the administrator (aka admin) as this duty is carried out voluntarily. Thus, he decided to assign a few other parents, who had been with the group for more than three years, as admins. The distribution of admin duties is to ensure the activities are monitored regularly and communications are moderated on the Facebook *wall*. This is to ensure that members will not create a stressful situation based on what they post, either a status or a comment. Members need to adhere by the rules of the group with the ultimate aim of supporting one another. When a post or comment is deemed to be inappropriate (in which it creates stress or sparks heated debate), the post or comment will be deleted.

With such a large number of registered users, which keeps increasing, it is paramount to investigate the prospects/efficacy of Facebook as a communication tool for the support group for parents of a child with ASD in Malaysia. The purpose of this study is to explore the purpose of parents joining the Facebook group, the activities they conducted, the types of support being exchanged, to what extent they found AM FB support group beneficial and the impacts of AM FB to themselves and their child with ASD.



Figure 1.1. Information page of Autisme Malaysia Facebook group

### 1.4 Objectives of the study and research questions

The purpose of this study was to explore the experiences of parents participating and communicating in the AM FB group. This study also investigated the impact of these experiences on the parents as individuals and also as members of the online community. To meet the purpose of this study, two research objectives were designed to obtain this goal, which was outlined below. Specific research questions were considered in order to achieve these research objectives. By answering the research questions, it was believed that the objectives would be achieved as well.

Objective 1: To explore the experiences of parents of a child with ASD in Malaysia participating in Facebook support group called Autisme Malaysia (AM)

Research Questions:

- a -What constitutes parents' online engagement in Autisme Malaysia?
- b - What kind of support is being exchanged in Autisme Malaysia Facebook support group?

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c - In what way do the linguistic and paralinguistic features in Facebook allow parents to exchange this support?

Objective 2: To investigate the impact of online engagement in Autisme Malaysia Facebook support group on parents of a child with ASD in Malaysia.

Research Questions:

a - To what extent does communicating support in Autisme Malaysia Facebook support group benefit or damage parents of a child with ASD in Malaysia?

b - In what way do these impacts affect parents' personally or professionally/ as individuals or members of the online community?

c - What competing discourses, if any, animate parents' narrative about their child with ASD, and how do parents mediate such discourses?

### 1.5 Significance of the study

The increasing number of parents joining Autisme Malaysia support group sparked an interest in investigating the reasons or motivation underlying their participation in the online group. In Malaysia, online support groups for parents of a child with ASD is rather a new area and there are very few studies (Mustafa et al., 2015; Roffeei et al., 2015) in this context. Therefore, studying the experiences of these parents could uncover issues and efficacy of Facebook as a communication tool for this support group for parents of a child with ASD.

The experiences shared on Autisme Malaysia Facebook *wall* provide an extensive overview of what these parents went through having to manage their child with ASD, as a similar study on personal blogs and chat rooms had revealed (Reinke & Solheim, 2015). This finding is valuable to healthcare providers, clinical practitioners, special education



practitioners, and researchers in designing support programs or interventions for these parents, particularly in Malaysia. It also sheds some light on considering Facebook as a communication tool for an online support group which could complement the readily available face-to-face support group conducted in hospitals in Malaysia.

Although the context of this study is focusing on parents of a child with ASD in Malaysia, there is not much difference when it comes to the prevalence of ASD issues around the world. Perhaps the experiences felt by parents in Malaysia have been experienced by other parents in other countries. Thus, there is an opportunity for this study to contribute to the field of ASD with a replication or comparative study in the future.

### **1.6 Scope of the study**

This study explored the experiences of parents of a child with ASD in Malaysia who were using Facebook as a communication tool for a support group. It investigated parents who were active users of the Facebook support group called Autisme Malaysia (AM). There were ethical guidelines on AM FB support group which members should adhere to and statuses which were offensive would be deleted by the admin and reminder would be given. This study investigated the parents' entire experience of using the Facebook group with no reference to the differences in gender, social economic status and the severity of their child's disorder.

### **1.7 Ethical considerations**

Careful consideration had been given when designing this study so that it would cause no harm to the participants. The participants were parents of a child with ASD and their participation in this study was voluntary. These parents originate from Malaysia and since the researcher comes from the same country with a similar background, the issue of cultural sensitivity can be minimised. There were no sensitive personal or cultural issues included in the research questions. Information about the research (Information Sheet) was

given at the beginning of participant recruitment so that the parents were clear of the purpose of the study. The consent form was distributed after parents had given their verbal consent to become participants of the study. They could withdraw their participation at any time without having to justify their reason. All data collected and used were of the participants' consent. They were also given the questions for the interview so that they had the freedom to not answer any of the questions that they may find offensive. Participants who might feel stressed when participating in the semi-structured interviews were given access to counselling (if needed) provided by the governmental and non-governmental agencies in Malaysia which are available through phone, e-mail or face-to-face. This service is available throughout different states in Malaysia. Although the researcher could not measure the stress level of the participants during the interview, the information about the counselling was provided in the Information Sheet that they received earlier. This study obtained full ethics approval (No. H0014173) by Tasmania Social Sciences Human Research Ethics Committee on 31<sup>st</sup> August 2014.

### **1.8 Conclusion**

As the first chapter of the thesis, this chapter had provided a general introduction to this study. It first provided background to the study, statement of the problem that led to this study to be conducted, and the purpose of the study, which included an overview of the Facebook support group being investigated, called Autisme Malaysia. The research objectives were explained, followed by research questions to be answered in order for the research objective to be achieved. This chapter then highlighted the significance of the study and described the scope of the study. Lastly, this chapter included the ethical considerations involved in this study.

The following chapter will examine the theories and concepts relevant to this study. The chapter is divided into three main sections: (i) support groups and social support, (ii)

communication, and (iii) social network sites, in which all related to disability and ASD presented in other literature. In each section, the researcher reviews and discusses the history, past research including the principles and strategies adopted, and lastly the justification of why it is of paramount importance that this study be undertaken in the Malaysian context.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.0 Introduction**

This chapter explores the history of support groups and social support. Past research in these areas related to disabilities and ASD are also highlighted. Although the study focusses mainly on online support groups and not face-to-face support groups, it is valuable to consider research on face-to-face support groups as they are the immediate predecessors of online support groups. This chapter also presents literature on computer-mediated communication for support groups. Research on communication among parents of a child with ASD in a face-to-face setting and online setting are discussed. The history of social network sites, including Facebook as the focus and research conducted in these areas is also highlighted.

### **2.1 Support groups and social support**

One of the most effective support groups can be traced back to 1980s in which clinical trial found it assisted in reducing tension, anxiety, fatigue and confusion of women with metastatic breast cancer (Hermann, 2001). Support groups in health-related context are usually led by survivors, group members (spouses or siblings), or trained professionals which involve little or no cost at all, and are unlike a licensed professionals-led therapy group that normally incur a fee and focus on in-depth personal growth. Support groups focus on learning to manage current concerns and situations (Hermann, 2001), giving and receiving support and practical advice, and offering friendship and encouragement to the people who participate in the group (emedicinehealth, 2016). The types of support groups include bereavement/grief counselling (e.g. suicide, miscarriage), medical (e.g. HIV, AIDS, cancer), weight loss, mental health/illness (e.g. bipolar, eating disorder), family (e.g. parents

with disabled child), and addictions (e.g. alcohol, drugs and gambling). The idea of people having similar experiences coming together encourages them to not only help themselves but others at the same time (King & Moreggi, 2007).

Social support is defined as “an exchange of resources between at least two individuals perceived by the provider or recipient to be intended to enhance the well-being of the recipient” (Shumaker & Brownell, 1984, p. 11). Since there is no universally accepted definition of social support, there is a consensus that social support is a multi-dimensional construct (Cohen & Wills, 1985; Cutrona & Russell, 1990). Social support has been claimed to be an important buffer of mental health and promotes health and well-being (Cohen, Underwood, & Gottlieb, 2000). It is the most well-reported psychological factors contributing to physical health outcomes (Uchino, Bowen, Carlisle, & Birmingham, 2012). Different theorists have suggested different classifications or dimensions of social support which include (1) emotional (the ability to receive comfort and security from others during times of stress, leading a person to feel that he or she is cared for), (2) network (the feeling of belonging to a group that shares common interests and concerns), (3) esteem (others’ bolstering of a person's sense of competence or self-esteem), (4) tangible (instrumental assistance where necessary resources are offered in order for one to cope), and (5) informational (providing one with advice or guidance concerning possible solutions to a problem (Cutrona & Russell, 1990). A key concept in social support is illustrated in Table 2.1. Numerous studies have been carried out on the effects of social support on individuals in support groups. Table 2.2 summarises some of the studies on online support groups and their classification or dimensions of social support.

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Table 2.1.

### *Key Concepts in Social Support*

Source	Concepts/Dimensions
Socially Supportive Behaviours (ISSB) & Arizona Social Support (Interview) Schedule (ASSIS) (Barrera, 1986)	Emotional, Tangible, Thanks
The MOS Social Support Survey (Sherbourne & Stewart, 1991)	Informational, Emotional, Tangible, Positive Social Interaction Affectionate,
Measures of Social Support (Sarason, Sarason, Shearin, & Pierce, 1987)	Emotional, Tangible,
Optimal matching model of social support (Cutrona & Russell, 1990)	Emotional, Informational (Support behaviours that matched the support goals)
Klem et al.	Personal experience, Quotes & Sayings, Prayers, Social Strain
Cohen & Hoberman (1983)	Tangible, Encouragement,

Table 2.2.

### *Studies on Online Support Group*

Source	Context	Research methodology	Samples	Dimensions of social support	Results
(Coulson, Aubeeluck, & Buchanan, 2007)	Huntington's disease	Content analysis	1313 messages	Informational, tangible, network, emotional and esteem	Informational support and emotional support were exchanged most frequently
(Coursaris & Liu, 2009)	HIV/AIDS	Content analysis	5000 postings	Informational, tangible, network, emotional and esteem	Informational support and emotional support were exchanged most frequently
(Ballantine & Stephenson, 2011)	Weight loss	Survey	145 members	Informational and emotional	Received little social support and showed a passive communication style
(Kim et al.,	Cancer	Content	177	Emotional	Factors affecting emotional

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2011)		analysis	participants		support given and received
(Evans, Donelle, & Hume-Loveland, 2012)	Postpartum depression	Content analysis	512 postings	Informational, instrumental and emotional	Emotional support was exchanged most frequently, followed by informational and instrumental support
(Love et al., 2012)	Cancer	Content analysis	320 postings	Informational, emotional and esteem	Emotional support was exchanged most frequently, followed by informational and esteem support
(Oh, Lauckner, Boehmer, Fewins-Bliss, & Li, 2013)	Health	Structural Equation Modelling	291 respondents	Appraisal, tangible, network, emotional and esteem	Emotional support has a positive and significant effect on health self-efficacy
(Yoo et al., 2014)	Breast cancer	Hierarchical regression analysis	236 patients	Emotional	Exchange of emotional support has a positive effect on emotional well-being for patients with higher levels of emotional communication
(Hajli, 2014)	Social commerce	Structural equation modelling	200 respondents	Informational and emotional	Social support has a positive effect on relationship quality and social commerce intention

### 2.1.1 Support group for parents of a child with a disability

Researchers have identified support groups for families of a child with developmental disabilities as one of the most notable developments in the field of support groups in the early 1980s (Schilling, 1988). During the last two decades, researchers had placed great attention on parent support groups (Mandell & Salzer, 2007). Medical-pathological model of disability, which was dominant during that time, began to be replaced by the social model of disability (Dowling & Dolan, 2001; Oliver, 1996). The latter model claimed that ‘disability’ was the result of the interaction between people with impairment and the physical, attitudinal, communication and social environment they lived in. All these had to change to ensure that people with impairment could participate and adapt with the

society. This social model had become very popular to assist in the setting-up of support group and as a result, parent empowerment and family support (Dunst, Trivette, Raab, & Masiello, 2008) and social support networking (Sarason et al., 1987) had gained greater emphasis. All these impacts were highly valued by those who participated in the support group. These impacts of support groups, theoretically, “are based on a solid foundation of psychological and sociological theories, including social comparison theory, social learning theory, the helper therapy principle, theories of experiential knowledge, and social support theories” (Salzer, 2002, p. 366). Hence, support groups implied such complex entity.

Parents of a child with special needs had long been using parent support groups in order to seek new information, share their experiences with other group members, or get emotional support (Bull, 2003; Huws et al., 2001; Solomon et al., 2001). Participation in the support groups yielded positive results as it decreased negative mood and stress (Beaudoin & Tao, 2007; Kerr & McIntosh, 2000; Preyde & Ardal, 2003; Stevens & Duttlinger, 1998), enabled better coping strategies (Silverman-Dresner, 1990; Singer et al., 1999), and created a sense of belonging, a sense of advocacy, and a change in perceptions of parents towards their child with a disability (Solomon et al., 2001). Further studies conducted to assess the parents’ needs in a support group concluded social and informational support (Douma et al., 2006; MacIntosh et al., 2005) and specific stress management strategies (Bitsika & Sharpley, 2004) as pivotal components. Despite all the reported benefits of parents’ support groups, very few parents participated in the groups available to them (Plass & Koch, 2001; Smith, Greenberg, & Seltzer, 2012). Parents who participated regarded support highly, such as meeting other parents and sharing feelings, rather than merely sharing information (Smith et al., 1994). However, after a decade, parents viewed support groups as the source for gathering information (Douma et al., 2006; MacIntosh et al., 2005), apart from obtaining social and emotional support. As more studies advocated positive outcomes of support groups for parents of a child with disability, Hogan *et al.* (Hogan, Linden, & Najarian, 2002)



dismissed it as it had the potential not to be therapeutic and could lead to negative experience as parents are involved in a critical and unpleasant social interaction that conjures in the support groups. Thus, due to these conflicting findings, it is paramount to further study the effectiveness of support groups for parents of a child with disabilities.

### **2.1.2 Support group for parents of a child with autism spectrum disorder (ASD)**

High levels of stress, social isolation, negative health outcomes, and marital dissatisfaction (Dunn et al., 2001; Estes et al., 2009; Sivberg, 2002) had been recorded among the family members as a result of the managing the child with ASD. In addition, ineffective and uncoordinated care system that provided accurate information for families of a child with autism (Jacobson & Mulick, 2000) also contributed to negative outcomes. These challenges might be common to families of a child with different kinds of disabilities but families of a child with autism might experience it to a greater extent (Dunn et al., 2001; Sivberg, 2002). Thus, support groups could be a powerful adjunctive resource for these families as sources of instrumental, informational and emotional support which were critical to well-being (Davison, Pennebaker, & Dickerson, 2000). In regards to the state of well-being, studies on parents of a child with ASD showed that higher levels of social support could be associated with lower levels of negative impact (Bishop, Richler, Cain, & Lord, 2007), decreased negative mood (Pottie, Cohen, & Ingram, 2009), depressive symptoms (Benson & Karlof, 2009; Ekas, Lickenbrock, & Whitman, 2010; Weiss et al., 2013), and alleviated psychological distress (Bromley, Hare, Davison, & Emerson, 2004). Parents experiencing a higher level of social support also reported a higher level of positive mood (Ekas et al., 2010; Pottie et al., 2009) which eventually contributed to their well-being. Social support was perceived to provide physical, emotional, informational and instrumental assistance that was considered as helpful and as part of one's social network (Dunst et al., 2008) which was especially crucial for families of child with disabilities. Social support was deemed to be critical for this group as it was linked to both positive and negative outcomes

predominantly in mothers of a child with ASD (Ekas et al., 2010; Smith et al., 2012). A 10 year longitudinal study on trajectories of well-being in mothers of adolescents and adults with ASD found that mothers reported an association of a larger social network size to lower levels of anxiety and depressive symptoms (Barker et al., 2010). A larger social support network also had shown improvements in multiple aspects of maternal well-being over time for mothers of adolescents and adults with ASD (Smith et al., 2012). Hence, this shows the importance of social support and social network size for families, especially mothers, of a child with ASD in ensuring their own well-being.

Research on face-to-face support groups had highlighted the importance of intervention during the support groups in order to (i) increase family's level of perceived resilience (Bozo, Anahar, Ateş, & Etel, 2010) (ii) foster self-efficacy by helping mothers to cognitively cope with their situation, to build skills to manage addressable stressors, and to engage better with the service system (Kuhn & Carter, 2006; Nachshen & Minnes, 2005). The intervention included teaching parents to (i) cope through emotion and problem-focused techniques and prioritise where they can make differences in their lives, and (ii) focus on parenting skills to increase parents' self-efficacy to manage their child's problematic behaviours successfully (Hastings, 2003; Singer, Ethridge, & Aldana, 2007). To ensure parents can manage their child's behaviour, not only the parents should play their part, a manageable and efficient service system is also crucial. This could only be accomplished when parents engaged constructively and actively with the service system through their empowerment and family centred models of service delivery (Brookman-Frazee, 2004; Koren, DeChillo, & Friesen, 1992; Nachshen & Minnes, 2005). The models had shown increased parental satisfaction with delivery of services (Trivette, Dunst, & Hamby, 1996), better results in child interventions (Brookman-Frazee, 2004) and increased parent self-efficacy (Brookman-Frazee, 2004; Dunst, Trivette, & Hamby, 2007). Such interventions through the delivery system, be it governmental or non-governmental organization, could

help parents to better emphasise their specific needs, identify the strengths and weaknesses of their social networks, and mobilise their networks when needed (Hansell et al., 1998). Hence, this indicates the importance of understanding the needs of these families of child with ASD and their active role in engaging with those who provide service system such as medical and educational services.

In order to ensure an effective delivery system, the quality of such support was more important rather than the quantity available (Smith et al., 2012). The type and quality of support offered, the person providing the assistance, and contextual issues might all play a role in determining whether parents would perceive support as beneficial (Ekas et al., 2010; Hogan et al., 2002). All these factors might alleviate stress felt by parents. A study found that certain types of social support might be perceived as negative 'social strain' and aggravate stress (Cranford, 2004). Hence, finding and engaging with the right kind of support is deemed important so that parents could fully utilise the support that they would receive. This was because support might erode after some time for parents of a child with ASD experiencing chronic stressors (Thoits, 1995). The reasons for the erosion of support in support groups were (i) the source of support is unsure how to help (Chesler & Barbarin, 1984), and (ii) the source felt their effort would not make a difference (Brickman et al., 1982). These factors could lead to the support groups being abandoned as parents could not see their role in supporting them. Despite receiving support from the support groups, Mroz and Letts (2008) claimed that families with a child who qualified for special education services still faced complex challenges, which included difficulties in diagnosis and variations on the kinds of services and supports received. All these call for research to investigate how informal social networks of parents of child with ASD could help them obtain and offer meaningful support in the support groups (Weiss et al., 2013).

Support groups would help these parents to share experiences among themselves on how to manage not only behavioural problems but also social problems that they encounter

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with their child with ASD. Learning from other parents' experience would give them an insight on how to go about managing their own child with ASD. "Family members who had 'been there' and shared similar experiences can support one another, provide critical information about where and how to obtain services, and, in some cases, can come together to advocate for needed resources and supports" (Mandell & Salzer, 2007, p. 119). Thus, communication among them is considered a valuable part of exchanging experiences. Communicating with each other in the support groups would assist them in getting the social and emotional support that is much needed to help them get through the challenges of managing a child with ASD. Due to partnership and communication problems that parents had to endure with professionals, they felt that more parent training and emotional support was needed and they valued regular, reliable and continuous support (Wodehouse & McGill, 2009). A comparative study between African-American mothers and Caucasian mothers showed that lower level of social support was a significant predictor of higher perceived negative impact of having a child with ASD among the latter (Bishop et al., 2007). It was important to note that historically, African-American communities had strong kinship networks that valued interdependence, religiosity, and spirituality (Brooks, Haskins, & Kehe, 2004) which might help protect them against negative experience or impact. This might also be the reason why African-American parents thought that support groups would not address their specific needs (Mandell & Salzer, 2007). "Other factors (such as child's and mothers' characteristics, socioeconomic status, cultural values, and interactions among these variables) could also contribute to the differences of perceived negative impact and disparities in services but differences in families' experiences had important implications for the development of support services" (Carr & Lord, 2013, p. 415). All these factors could affect parents' views on the effectiveness of support groups which may be the variables to be considered in this study.

Studies of parents of diverse ethnic background bringing up a child with ASD are important to be carried out so that researchers can further understand these parents' perceptions and experiences. This is because not much research has been done or reported on parents of different ethnic background other than Caucasians. This is also to agree or dispute the claim that support groups generally appealed to more educated, married, suburban Caucasians (Katz et al., 2002; Osborne, Ostir, Du, Peek, & Goodwin, 2005) as they were more comfortable discussing private feelings and experiences with others, due to the cultural factors. Greater resources and time encouraged them to find or initiate such groups in their communities, thus increasing access to support groups (Mandell & Salzer, 2007). Thus, conducting research on families of a child with ASD of different cultures and ethnic background is pivotal.

Many studies had been conducted on social support and its effect on other variables among parents in bringing up a child with ASD. Bromley *et al* (2004, p. 420) conducted "a study among mothers supporting their child with autistic spectrum disorders in The United States found that mothers experienced high levels of psychological distress due to low levels of support from their family members". Bringing up a child with higher levels of challenging behaviour was also another factor of this psychological distress. This finding is consistent with other previous studies' results in which informal social support was associated with maternal well-being among families bringing up a child with ASD (Dunn et al., 2001; Gill & Harris, 1991; Henderson & Vandenberg, 1992; Wolf, Noh, Fisman, & Speechley, 1989). These results suggested "a need for specific and, most importantly, on-going post-diagnostic support and counselling for those mothers" (Bromley et al., 2004, p. 421). Support and counselling for mothers may not necessarily come from an expert as they could also informally come from other mothers who go through the same experience of bringing up a child with ASD. In fact, a 'self-help' focus on family training, advocacy and family-to-family support might achieve more (McGill, Papachristoforou, & Cooper, 2006).

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This is where support groups fill in the gap of ‘self-help’. This is further supported by Lam *et al.*, who argued that the fact parents of a child with ASD experience more emotional stress than the parents of typically-developing children, “mutual support groups or self-help groups would be helpful in supporting them and enhancing their resilience” (Lam, Wong, Leung, Ho, & Au-Yeung, 2010, p. 373). In addition, the influence of self-help groups had been extended on the internet, (e-mails, chat rooms, bulletin boards, and other internet communities) primarily emphasising peer support for mental health patients and carers (Davison *et al.*, 2000). Thus, there is a high possibility that self-help groups on the internet could probably cater to parents of a child with disabilities, particularly a child with ASD.

When researching on support groups for families of a child with disabilities, much focus was given on the participation, especially parental participation. Most of this research was quantitative in nature (Beaudoin & Tao, 2007; Grande, Myers, & Sutton, 2006; Kerr & McIntosh, 2000; Preyde & Ardal, 2003; Silverman, 2014; Singer *et al.*, 1999; Solomon *et al.*, 2001). Further search on the research of support groups for parents of a child with ASD revealed evidence of quantitative design (MacIntosh *et al.*, 2005; Mandell & Salzer, 2007) and a few adopted qualitative design (Alat, 2006; Carter, 2009). Hence, there is a need for research adopting qualitative design in this area. Another crucial point to highlight is related to participant recruitment that had been employed by other researchers which may affect their research’s findings. Willingness and consent of the families of a child with ASD to enrol in research were probably influenced by the specific methods of recruitment (e.g. collaboration with a trusted source of medical care, the inclusion on the research team of staff of similar ethnicity, monetary incentives, test results, information about other services available in the community, evening, weekend and in-home assessment opportunities, and reimbursement for child care expenses, transportation provision) (Hilton *et al.*, 2010). Thus, the extent to which these methods influenced research findings needs to be investigated. The effectiveness of such strategies in intervention research was also paramount (Carr & Lord,

2013) as participants were willing to participate in those research merely to obtain all those 'incentives'. Apart from this, more research had started to look into families of heterogeneous ethnicity which included African-American, Mexican, and Asian (Chinese, Korean and Japanese), and therefore it was vital for ongoing studies on ASD to strengthen efforts to incorporate the entire range of race and ethnicity that will result in full depiction of the human population (Hilton et al., 2010).

### **2.1.3 Research on online support groups**

#### ***How online support groups started***

The rise of the internet in the 90's has given a new breath to support group. The internet has drawn people closer despite the geographical distance, time difference and ethnicity and resulted in the rise in the number of support groups for various purposes. These groups are available on a range of topics, which are professionally-led or patient-led. The internet has proven to enhance or extend face-to-face support networks in terms of providing greater access to individuals who are often geographically separated as the online support groups often involved larger and easier to maintain network of people (Drentea & Moren-Cross, 2005; Ellison, Steinfield, & Lampe, 2007; Lampe, Ellison, & Steinfield, 2006; Ye, 2006). The first online support group was initiated by the professionals in the health-related field in which the aim was to offer informational support and emotional support to patients. This was commonly known as formal online support group whereas informal online support group was usually instigated by patients or carers/families of the patients. With the advent of electronic list-services and the internet, opportunities for support and information-sharing had increased through the use of online communities (Shedletsky & Aitken, 2004) by the formal and informal groups, utilising e-mails, bulletin boards and chat rooms as the platform for discussion. An online support community or group is an internet-

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based space for people to exchange aid and assistance through social and interpersonal relationships.

The internet cancer support group, for example, was dated back in 1995 when McTavish *et al.* (1995) found that it gave cancer patients a source of support and health information and consequently reduced social isolation and increased personal empowerment and self-esteem. It was also found that an extensive proportion of breast cancer patients used the internet for informational support with those of white race/ethnicity with higher income or education being more likely to use the internet as a source for breast health issues (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002). Other studies involving different participants using online support groups produced similar positive results; a great deal supporting each other (Bar-Lev, 2008; Im et al., 2007; Miller & Gergen, 1998). However, only 7% - 10% of cancer patients went online in 2002 to seek information or support as they were doubtful of the reliability of the medical information that they found online (Diefenbach et al., 2009; Raupach & Hiller, 2002). This, however, contradicted the study conducted by Eakin and Strycker (2001) in which many cancer patients felt more comfortable to find information over the internet than to use the traditional cancer support services. As the number of cancer patients using online forum discussion increased, they reported positive attitudes towards the online support group as it provided emotional support, interactions, and information (Im et al., 2007). Apart from the reported positive attitudes as a result of using online forum discussion, research also found that individuals felt more satisfied with online social support networks as they could easily disclose sensitive information to network with weaker ties (not family members or close friends) due to the lowered interpersonal risk and the advantages of obtaining more diverse information about a problem/issue (Wright, Banas, Bessarabova, & Bernard, 2010; Wright & Miller, 2010). Thus, it can be claimed that the internet can empower and inform cancer patients, and provide social support, but it can also be intimidating, confusing, and frightening (Penson, Benson, Parles, Chabner, & Lynch,



2002). These findings could be similar or different from the findings of this study investigating parents of a child with ASD in Facebook support group.

### ***Multidisciplinary research areas on online support groups***

Online support groups had provided a vast area of research interests beyond illness/medical and patient-related issues. Royal (2005), for example, found that women had equal access to the internet but they felt less comfortable participating and less welcoming. In a different setting and not gender-related, Ye (2006) studied international students in an online support group which resulted in them receiving more information and feeling less stress. In addition, Kuster (2007) highlighted the value of information shared in online groups, including the fact that online support groups could provide information through internet links. Online support groups had also been proven to play an imperative role in promoting mental and physical health (Uchino et al., 2012) for people dealing with cancer, HIV/AIDS, pregnancy, and weight loss, and prevent potential accessibility by providing helpful information online for young suicidal individuals (Scherr & Reinemann, 2016). This shows that online support groups are applicable to a vast group of people with the sole purpose of seeking and obtaining social support. As more users utilised the internet, online support communities were mushrooming at a fast pace and quickly becoming one of the most frequently accessed resources (Coulson et al., 2007). The success of the online support communities depended on the members' behaviours that benefited the community as a whole, as they were social entities comprised of people and their relationships (Chiu, Huang, Cheng, & Sun, 2015). Only when the members act and behave according to the social norms of the online community will it generate positive outcomes to its members.

As the main focus of this study was the informal online support group that was led by parents of a child with ASD, it was paramount to highlight some of the past research which had a similar emphasis. Yoo (2014) investigated the communication perspective into online health-related support groups by examining the important role sociocultural factors

play in motivation to use online support groups. His sample was dementia support groups which was comprised of the primary caregivers (mostly family members) of dementia patients, rather than the patients themselves (as in other online support groups' studies involving illness-related patients, such as, cancer, diabetes, HIV/AIDS). His first aim was to investigate the types of support the dementia caregivers seek to receive within the online support groups, and what made his study different was that sample involved Koreans. It was substantiated that the study was crucial due to the lack of the Korean setting in the literature as most studies (Dilworth-Anderson, Williams, & Gibson, 2002; Miesen, 2004) had reported the impact of caregiving on emotional distress among Caucasian caregivers in the United States only. It is important to emphasise non-Caucasian caregivers' samples because dementia is a disease with various sociocultural factors attached (e.g., family values and structure, norms, customs, etc.). Past research found that Korean caregivers reported a significantly higher level of stress than any other ethnic group (Lee & Farran, 2004; Youn, Knight, Jeong, & Benton, 1999). Thus, Yoo (2010) explored the sociocultural factors associated with the Korean sample's high emotional stress by analysing the participation and postings in the online support communities. A similar concept of analysing participation and postings is adopted in this study as there is a lack of literature examining online support groups involving parents of a child with ASD in Malaysia. Most past studies were looking at Caucasians in the USA, with a few involving African-American samples, but even fewer involving Asians, especially Malaysians. All these studies were mostly examining online support groups that were using e-mails, bulletin boards and chat rooms. This study, however, looks at the online support group using Facebook as a platform. Studies involving Facebook is rather new and innovative in the Malaysian context.

Another research investigating participation in online communities was carried out on people seeking behaviour change, such as weight loss or smoking cessation (Ploderer, Smith, Pearce, & Borland, 2015). In this study, some people could easily share their

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experiences, feeling at ease sharing their changed behaviour online while some were reluctant. The latter often had less contribution online as they foresaw it as potential embarrassment due to their failed attempt to change their weight loss or smoking behaviour (Purpura, Schwanda, Williams, Stubler, & Sengers, 2011). People were concerned about the impression they might receive, often inadvertently from family, friends, co-workers and acquaintances, if contributing to social network sites (Morris, Teevan, & Panovich, 2010; Newman, Lauterbach, Munson, Resnick, & Morris, 2011). Impressions were highly likely to be more extreme when making them online compared to face-to-face due to the reduced feedback to dampen emotional expressions (Joinson, 2003). As the feedback or comments can be deleted by the receivers, Facebook has become the users' preferred platform. Those who always contribute to the online communities group were members who were successful with their behaviour change and yet their profiles still remained anonymous (Cobb, Graham, & Abrams, 2010; Maloney-Krichmar & Preece, 2005). Individuals who joined such online communities but were reluctant to actively contribute were, in fact, eager for a change of behaviour and yet they still kept the old habits. They were characterised as ambivalent socialisers who typically preferred to read rather than actively contribute (Ploderer et al., 2015). Hence, this resulted in interaction becoming lean within groups as efforts to encourage personal contributions might be undesirable and counterproductive. This, in turn, led to difficulties in keeping members committed, attracting new members and encouraging contributions, which are ongoing challenges that lead to many online communities to go quiet and inactive (Kraut & Resnick, 2012). Thus, members play an active role in ensuring the sustainability of an online community/group.

Apart from the participants of the studies involving online support groups (caregiver/families rather than patients themselves) and the setting of the studies (Asians rather than Caucasians), another important highlight is the question regarding the reasons people select an online discussion group instead of a face-to-face group. The reasons may

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include frequency of interaction, 24/7 availability, a sense of anonymity, convenience, no geographical boundaries and the lack of pressure to talk in a group. Although this study is not making a comparison between online support groups using Facebook and face-to-face support groups, it is paramount to highlight the reasons for choosing the online option which has been reported in the past studies. This is because these reasons could illustrate the motivations for the parents' participation and also their behaviours when communicating in the online support group (Autisme Malaysia Facebook support group). It was found that people with low self-esteem were more likely to use the internet more frequently (Forest & Wood, 2012; Mesch, 2006), hence giving them the opportunity and ease to participate in online support groups compared to a face-to-face setting. Zimmerman (2013) reported that severely disturbed adolescents were more comfortable expressing themselves online instead of face-to-face settings. Thus, people with low self-esteem or of high-risk could take advantage of being anonymous in the online support groups as the sense of anonymity in the nature of online communication might actually increase the quality and depth of members' responses through personal disclosure, reciprocity, and personal acceptance (VanLear, Sheehan, Withers, & Walker, 2005). Another study highlighted that "although people with low self-esteem considered Facebook an appealing venue for self-disclosure, the low positivity and high negativity of their disclosures elicited undesirable responses from other people" (Forest & Wood, 2012, p. 295). Thus, it can be said that Facebook serves both positive and negative outcomes to its users, depending on the purpose of the users joining a Facebook group. Although it was said that the online support groups offered similar value to their members as that of face-to-face support groups (Turner, Grube, & Meyers, 2001), the value of the former could surpass the latter. Therefore, it is pivotal to carry out this current study to determine if this claim is justifiable using Facebook as a platform rather than other means of online support group (e-mails, chat rooms and bulletin board).

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As discussed earlier, the online support groups had utilised different platforms on the internet, including e-mails, bulletin boards and chat rooms. A study analysing 1718 e-mails on parental use of an online support group for their child with disabilities had been implemented in the USA (Aitken, 2008), and the findings suggested that parents used the group for the following purposes: (a) expressive story-telling, (b) seeking and giving advice, (c) seeking or offering validation or encouragement, (d) seeking or providing information, (e) seeking or suggesting resources, and (f) sharing celebrations and telling success stories for hope. As this study was conducted in the USA involving Caucasians, it is crucial to see if a similar study conducted in Asia (Malaysians' Malay) would yield similar findings. Although past studies have found online support groups to be of benefit to its participants or members, it is without a doubt that there are pitfalls of the platform that is being used. For example, although e-mails could be sent to all members in the online group through their e-mail address, it does not allow for synchronous communication. There is also the possibility that the e-mail is not sent due to incomplete or wrong e-mail address, for example. It may also take a while to compose an e-mail as it is commonly associated with a longer piece of writing and thus delays the support that the participants are looking for after the e-mail is sent. With a chat room, users can receive responses quickly as it uses synchronous communication and also it allows the users to interact with multiple users at the same time. However, it may not be feasible to look back at their earlier communication threads due to the large amount of communication which may have taken place. Unlike Facebook, users can easily search for people or topics being discussed earlier by typing appropriate keywords in the Search tab. They can also easily save the post which they find useful on the Facebook *wall* by clicking on the 'Save Post' button. Apart from this, Facebook contains features which allow both synchronous and asynchronous communication to take place simultaneously. Other features include feelings intensifier, buttons (Like, Comment and Share and recently updated Love, Sad, Angry) and place check-in. All these features make

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Facebook an easily accessible and feasible communication platform to be used for online support groups.

Time invested online has also been of interest to researchers in social sciences. Both benefits and drawbacks have been reported as the results of how much time spent on the internet to various aspects of individuals' life. Some of the drawbacks reported for individuals, who invested time online rather than investing in face-to-face relationships, included reduced contact, network size, density, and quality of interaction (Cai, 2004), slight but significant increase in loneliness and depression over time (Kraut & Resnick, 2012), and decrease in social and familial involvement (Kraut & Resnick, 2012). These drawbacks were evident to a certain extent as a study revealed that individuals' internet use and depression were associated in much more complex ways as depression was mediated and facilitated by appraisals of social support offered by online network members (McKenna, Green, & Gleason, 2002). Increased online social support use resulted with the decreased face-to-face support network as heavy internet users often turned to computer-mediated support to compensate for traditional face-to-face social support interactions (Ellison et al., 2007; McKenna et al., 2002; Xie, 2008). However, later research found that face-to-face support groups' network satisfaction had a larger effect on reducing depression than Facebook support groups' network satisfaction (Kevin et al., 2013) and more time spent time on Facebook did not reflect higher engagement (Junco, 2012). It is worth highlighting that both these findings were tied to the specific population of the studies, which were college students. The effect of reduced depression when using computer-mediated social support may be of greater benefit to individuals who were socially isolated or living with a stigmatized health condition, such as HIV/AIDS or a disability (Wright & Bell, 2003; Wright & Miller, 2010), whereas other individuals may prefer face-to-face support (Wright, Banas, et al., 2010; Wright & Miller, 2010). Due to this reason, it is crucial to identify who could benefit from computer-mediated versus face-to-face social support in order to develop

appropriate supportive interventions for individuals dealing with a variety of issues within different populations or samples. Hence, it is highly likely that findings of this study may be different and diverse due to the samples and setting of the study. As parents of a child with ASD are considered as a stigmatized group, it is highly possible that they prefer online support group over face-to-face support group.

### **2.1.4 Research on online support groups for parents of a child with a disability**

Many studies focused on the use of computer-mediated support groups by individuals or groups with certain types of disability, illness, or addiction, but very few focused on the use of online support groups by parents of special needs children (Alat, 2006; Baum, 2004; Clifford, 2011; Han & Belcher, 2001). Among these, only a handful investigated parents of a child with ASD (Alat, 2006; Carter, 2009; Clifford, 2011; Huws et al., 2001). These parents used support groups to obtain informational, emotional, and esteem support (Huws et al., 2001) and positive outcomes that were gained when participated in online support group include increasing advocacy, providing a sense of connectedness or social support and empowerment (Carter, 2009). Although a comparative study conducted between parents of a child with ASD who used and did not use online support group showed no significant difference, parents who participated were satisfied with the support they received and found the online group to be very helpful (Clifford, 2011). This indicates that when the needs of the group members are catered to, they reap the benefits of using online support groups.

Most studies had addressed reasons for parents to turn to online support groups instead of traditional sources, such as immediate family members, neighbours, educators, and professionals. One of the reasons was due to being misunderstood by immediate support networks such as spouses, parents and friends (Mickelson, 1997). Findings from various research (Brashers, Neidig, & Goldsmith, 2004; Wright, Rains, & Banas, 2010) had claimed

that many individuals found it difficult to obtain appropriate support from strong ties (such as close friends and family members) because they felt that these potential sources of support lack experience or had limited information about certain problems, or they felt uncomfortable discussing their sensitive problems with members of their close tie support network because of the fear of being judged or patronised. Thus, it is critical to investigate if these reasons also underpinned the participation of parents of a child with ASD in this study. The findings could assist health professionals, educators and counsellors to improve or design new intervention programs (Alat, 2006). The participation of professionals in online support groups for parents was highly valuable as it would give new insight on improving traditional pathological models of disability (Jones & Lewis, 2001). All these studies were looking at Western settings including Alat (2006) who looked at parents of a child with ASD in Turkey, and until the time of this writing, very few studies were reported in Asian settings. Therefore, it is pivotal to conduct a study on the effectiveness of online support group among parents of a child with ASD in Asia, particularly in Malaysia.

### **2.2 Research on communication of parents of a child with ASD**

ASD is a developmental disorder characterised, in part, by language and social deficits. Although most studies emphasise a great interest in investigating children with ASD, the parents or carers are also given an equal importance in research. Since Kanner (1943) first described autism as ‘a neuropsychiatric disorder characterised by severe and sustained impairment in social interaction, deviance in communication, and patterns of behaviour and interest that are restricted, stereotyped, or both’, some clinicians and research workers had reported that parents of a child with ASD also exhibited deficits in social interaction (Landa et al., 1992; Wolff, Naryan, & Moyes, 1988). It was reported that “parents of autistic individuals generally disdained small talk and were overly formal (pedantic) in their communications” (Landa et al., 1992, p. 245) and “displayed abnormal pragmatic behaviours (disinhibited social communication, awkward/inadequate expression,



and odd verbal interaction) in social conversation due to being influenced by individuals/children with ASD” (Landa et al., 1992, p. 246). Another study (Smith et al., 2012) looked into the positive and negative support received by mothers of a child with ASD from their social network which resulted in six types of positive support including emotional and instrumental supports. This study also highlighted how negative aspects of social interactions and exchanges had a detrimental impact on well-being of the former as the network members criticised the mother’s involvement in her child’s life; blamed her for her child’s problems; made excessive demands on the mother; or made the mother feel uncomfortable (Smith et al., 2012). These studies show that communication or social interaction among the network of mothers of a child with ASD can either be comforting or intimidating. This again calls for similar research to find out if this claim of the negative aspects of online social interactions is indeed true.

As for other research related to a child with ASD, research concerning the parents/carers was also carried out in a Western setting involving Caucasians. Very few studies were looking at Asian settings involving Asian parents/carers and it is paramount to investigate these samples as the number of children being diagnosed with ASD in Asia is on the rise (United Nations, 2006). It is crucial to see if online support groups can be of benefit to the parents of a child with ASD in Malaysia.

### **2.2.1 Computer-mediated communication**

Research into communication in an online setting has generated interest from different disciplines. This includes business and management, education, and advertising. Some of the studies that had been carried out included gathering business intelligence from blogs (Chau & Xu, 2012), and instructional strategies for using social media in formal and informal learning (Chen & Bryer, 2012). These various research fields indicate the importance and value of online communication toward society at large. Preliminary analysis

of a randomised trial suggested that the use of a multimedia program to educate prostate cancer patients about their treatment options after diagnosis was successful in reducing their decisional conflict and reducing decisional regret over time (Diefenbach, Mohamed, & Hall, 2008). These studies, among others, signify the importance of research of computer-mediated communication in various disciplines.

### **2.2.2 Research on computer-mediated communication in online support groups**

With the rapid interest in the use of internet and the presence of various online communities, researchers, particularly in communication, sociology and psychology, have begun to put high attention on the communication patterns that take place online. Types of communication, communication strategies adopted by users online are some of the areas being investigated. When investigating communication in an online support group setting, interpersonal communication came into play in which statement of support and self-disclosures were two most common types (Wood & Smith, 2005). Participants frequently engaged in self-disclosure as they shared intimate details and emotions which had therapeutic value that conjured empathetic statements, complemented by gratitude expressions for the support given by other participants (Miller & Gergen, 1998). Engagement in computer-mediated social support groups had been reported to help patients effectively cope with their chronic illness during its course by increasing feelings of self-efficacy and information competence and by decreasing breast cancer-related challenges and negative emotions (Han et al., 2008; Rice, 2006; Shaw et al., 2007). All this can be achieved through communicating using appropriate language. The key concepts in language use for support in online communication are illustrated in Table 2.3.

Table 2.3.

*Key Concepts in Language use for Support in Online Communication*

Concept	Source
Verbal/written language	Language Expectancy Theory Burgoon & Burgoon (2001)
	Symbolic Interactionism (Blumer, 1969)
	Empathic communication (Preece, 2000)
	Linguistic Softeners (Wallace, 1999)
Non-verbal language	Social Presence Theory (Gunawardena, 1995; Short, Williams, & Christie, 1976)
	Media appropriateness (Rice, 1993)
	Linguistic Softeners (Wallace, 1999)
	Emoticons (Preece, 2000)
	Netspeak acronyms (Lehnert, 1998)

***Discourse***

One of the frequently studied areas of communication, be it online or offline, is discourse. Discourse can be defined as an extended stretch of “contextually sensitive written

and spoken language produced as part of the interaction between speakers and hearers and writers and readers” (Candlin, Maley, & Sutch, 1999, p. 321). The notion of ‘contextually sensitive written or spoken language’ refers to the context or setting of the discourse and how it is being investigated or analysed, for example, from a linguistic practice or social/institutional practice. In this study, ‘discourse’ is defined as “socially constructed ways of knowing some aspects of reality which can be drawn upon when those aspects of reality have to be presented, or, to put it another way, context-specific frameworks for making sense of things” (van Leeuwen, 2009, p. 144). The focus of this current study is to understand aspects of the reality of social support in the context of online communication adopting Facebook as a platform. The idea of intertextuality playing a part as a discourse of health (social support) and new media (Facebook) is presented in this study. Discourse in the context of healthcare can be seen as a central activity which endeavours to promote positive (or otherwise) outcomes and patient satisfaction (Harvey & Adolphs, 2012). However, instead of *the patient*, this study refers to *the users* of Facebook who join the online support group. Previously, media discourse denoted discourse as “the interactions that occur through a broadcast platform, spoken or written, to a non-present reader, listener or viewer, who is unable to make instantaneous responses to the producers(s) of the discourse” (O’Keeffe, 2012, p. 441). However, this notion is changing with the emergence of new media, particularly social media. The users of social media, in the context of this study, referring to the members of the Facebook social support group, are able to produce the interactions and response synchronously or asynchronously.

Many studies have adopted discourse analysis in various contexts, using different approaches or perspectives such as sociocognitive, discourse-historical, dialectical-relational and corpus-linguistics. The choice of the approaches/perspectives adopted in the studies depends on the focus and purpose of the discourse analysis. The studies on discourse range in areas such as politics (Vaara, 2014), institutions (Ybema, 2014), media (O’Keeffe, 2012),

education (Van Dijk, 1981), and marketing (Kenning, 2008). Relational dialectic perspective is considered suitable for this study as it refers to a knot of contradictions in a relationship or perpetual interplay between contrary or conflicting tendencies (Griffin, 2011). The four concepts underpinning relational dialectics are (i) relationship is non-linear; (ii) relational life is influenced by the change; (iii) contradiction is central in relational life; and (iv) communication is fundamental in shaping and negotiating relational contradictions (Richard & Turner, 2010).

### *Narrative as a form of discourse of online communication*

Narrative refers to the narrative statement, be it the oral or written discourse that undertakes to tell of an event or a series of events. The narrative is an important component of the discussion in most online support groups. The narrative in a form of story-telling is a central communication skill involving cognitive, knowledge, and language skills (Soto & Hartmann, 2006). The narrative is critical in meaning-making and social-psychological understanding (Genereux & McKeough, 2007). Many studies had been conducted on the purposes and effects of story-telling. People reflected on their difficult experiences and used story-telling to make sense of those experiences (Koenig & Trees, 2006). In addition, families commonly used story-telling to convey values to their children (Kyratzis, 2005) in which family stories tend to be highly personal (Sherman, 1990). However, in this study, parents in the online support groups (AM FB) were comfortable in sharing their family stories with other members.

Narrative discourse is produced by “the action of telling in the same way that any enunciation was produced” (Genette, 1980, pp. 25-26). It can be told in verbal or written discourses. Using narrative of family stories in an online setting is commonly known as self-disclosure. Self-disclosure of difficult situations had been proven to have positive effects on an individual’s well-being (Pennebaker, 2003). As people who participated in an online support group had different experiences, they mediated these differences based on their

dialogic interactions (Innes, 2007), which might be imperative in an online support group setting. This is because the lack of non-verbal features (facial expressions, tone of voice, gestures) encourages misinterpretations of the intended meanings among the participants/members in the online support groups. This struggle of managing online communication to avoid communication being misinterpreted by others in the online communities was also highlighted by Kevin et al. (2013). Kevin suggested that “satisfaction with one’s support network in face-to-face and computer-mediated contexts was often contingent upon the complicated process of managing difficult individual coping needs while simultaneously attempting to handle delicate relational concerns when seeking support” (2013, p. 44). Although many studies had highlighted the benefits of narrative discourse between parents and children, such as “developing a more advanced understanding of others’ thoughts and feelings” (Guajardo & Watson, 2002, p. 320), and promoting health benefits (Pennebaker & Seagal, 1999), similar benefits could also be applied between adults. The narrative discourse which included negative emotions helped the individuals to learn how to negotiate social relationships and manage their own affect (Lagattuta & Wellman, 2002). Research also claimed that “both emotion-laden discourse and positive affect facilitated the construction of emotional and relational understanding and it seemed plausible that emotional and relational understanding was enhanced when emotion was discussed in the context of shared positivity” (Laible & Song, 2006, p. 207). Hence, the findings of this study will either support or dispute these claims.

### **2.3 Social Network Sites (SNS)**

The rise of Social Network Sites (SNS) was dated back to 1997 with “SixDegrees.com, where users were allowed to create profiles, list their friends, and in 1998, surf the friends lists” (boyd & Ellison, 2008, p. 214). However, the service was closed in 2000 as the founder believed that it was ahead of time and users had limited activity after

accepting 'Friends' and were uninterested in meeting strangers. Many community tools were designed from 1997 to 2001 which allowed users to create personal, professional and dating profiles and also identify 'Friends' without asking approval for those connections. The height of SNS triggered "websites focusing on media sharing, such as Flickr (photo sharing), Last.FM (music listening ), and YouTube (video sharing) to implement SNS features and become SNS themselves" (boyd & Ellison, 2008, p. 216). However, some tools gained more popularity outside of the United States (US) and those which were popular in the US had some hiccups which led them to lose their users. It was claimed that more than two-thirds of the world's online population visited and participated in social networks and blogs and this made social media surpass e-mail as the most popular online activity (Benevenuto, Rodrigues, Cha, & Almeida, 2009). The various SNSs offer different features that allow users to customise their personal profile (details and picture), maintain friends' list, post status and pictures, watch others' activities, make new friends, and join various interest-led groups. Studies had indicated that participation in social media such as blogs and SNSs might help to increase self-esteem, as well as satisfying social needs and enhancing greater social capital (Courtois, All, & Vanwynsberghe, 2012; Steinfield, Ellison, & Lampe, 2008; Valkenburg, Peter, & Schouten, 2006). Hence, this makes Facebook a popular choice among its users worldwide. "The types of social network sites and the year they were launched" (boyd & Ellison, 2008, p. 212) are illustrated in Figure 2.1 below.

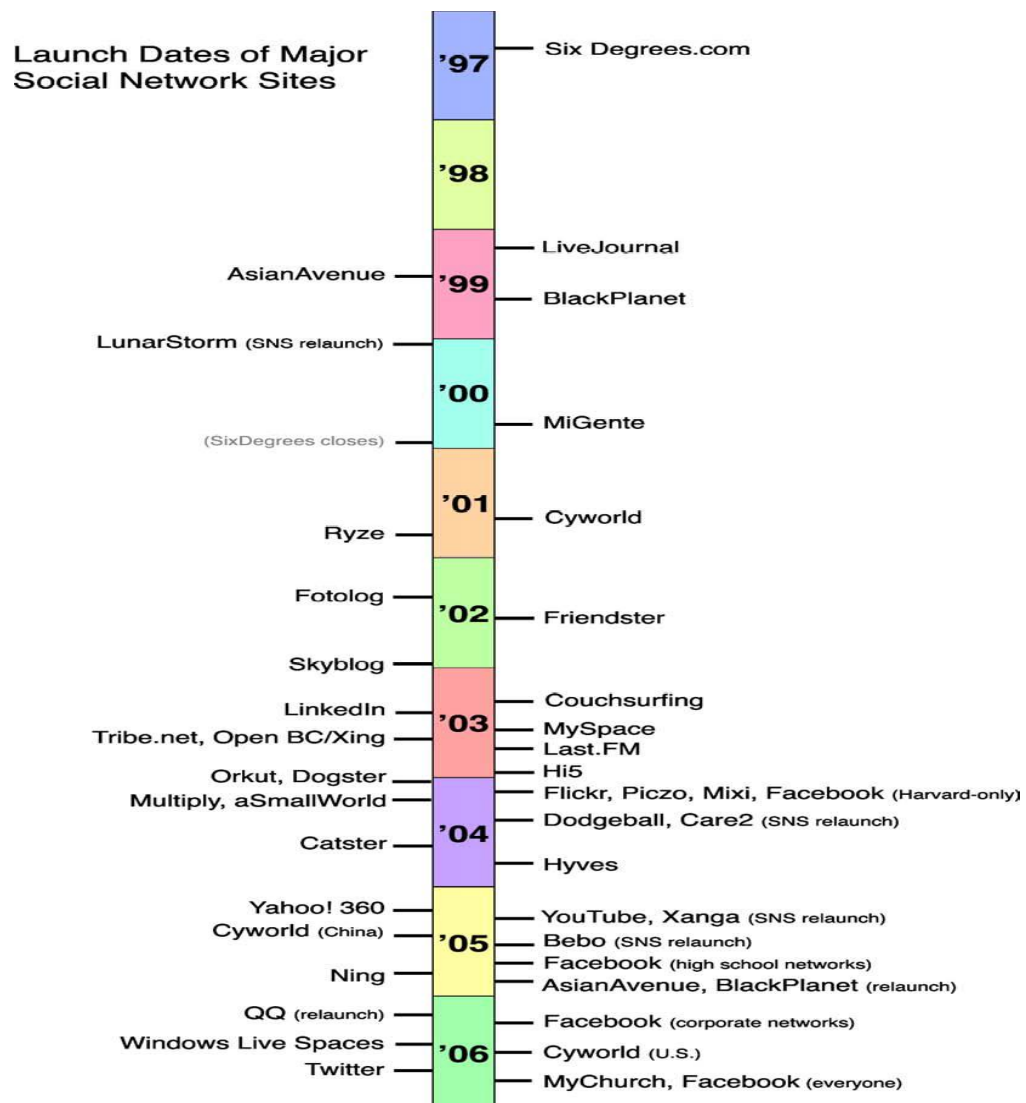


Figure 2.1. Timeline of the major SNSs introduced and re-launched with SNS features.

## 2.3.1 Emergence of Facebook as a SNS

Unlike other SNSs, Facebook was first introduced in 2004 and catered only to students studying in Harvard (Cassidy, 2006). To access the college network, users must have Harvard.edu e-mail address and the site was kept relatively closed and private. Then, the network expanded to include high school students and only in 2005 did Facebook finally open up to the public. This change allowed users to access the network but they still needed a valid .com address and administrator's approval to access or join groups on Facebook. Facebook had changed its privacy setting to cater to the users' increasing awareness of their safety online and these privacy settings helped to attract more than 1.13 billion users up to



June 2016 (newsroom.fb.com). Although Facebook has undergone changes over time, “the core Facebook experience remains unchanged from the beginning, always focusing on the users’ ability to (a) post self-relevant information on an individualised profile page, (b) link to other members and create a “friend” list, and (c) interact with other members” (Wilson, Gosling, & Graham, 2012, p. 208). As a result, Facebook had painted a remarkable success by creating a massive new domain where millions of social interactions took place and four billion pieces of content were shared per day by the users (Facebook, 2016). With such a myriad of interactions taking place on Facebook, it is a promising area to research.

### **2.3.2 Emerging research on Facebook (FB)**

Activities performed on Facebook (connecting to others, expressing preferences, providing status updates) can leave a wealth of concrete observable data. As a result, Facebook can “create great opportunities to study aspects of human behaviour which has been previously difficult to assess, for example, making friends and chatting” (Wilson et al., 2012, p. 204). Research on Facebook was initially dominated by areas of business and marketing, celebrities’ fan page and brands pages, and health and medicine. As Facebook gained more popularity, the research areas have expanded to education (college students, teaching and learning) and psychology. Many studies have been conducted on Facebook which include Lampe, Ellison, and Steinfield (2006) who found that Facebook users are more likely to ‘search’ for people with whom they have an offline connection than ‘browse’ for complete strangers to meet. Others include Golder, Wilkinson, and Huberman (2007) who examined ‘Friending’ and messaging activities of 362 million messages exchanged by over four million Facebook users. Therefore, it is useful to regard Facebook as an ongoing database to study human behaviour as information is added almost every day. Since users on social network sites leave online traces, they offer unparalleled opportunities for researchers. Some of the aspects of Facebook which have been investigated by researchers included

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reasons or motivation on engagement, trust, identities, online image, information and disclosure, privacy, Facebook features and users' behaviour.

The first aspect when studying Facebook could be looking into what made users create an account, join Facebook groups and participate actively in communication on Facebook. There were two specific "socially oriented motives for using Facebook: (a) *interpersonal motives*, or the goal/desire to use the medium to develop, enhance, or maintain relationships; and (b) *social integrative motives*, which involve using the medium in an attempt to find information about relational partners and helping individuals feel connected with others" (Kevin et al., 2013, p. 45). Interpersonal and social integrative motives had been claimed to increase interpersonal communication, relational development and maintenance, and social involvement in the online communities in several studies that had been conducted (Muhtaseb & Frey, 2008; Papacharissi & Rubin, 2000; Wright, 2002).

In analysing trust on social network sites, (Dwyer, Hiltz, & Passerini, 2007) argued that trust and usage goals might affect what people were willing to share—"Facebook users expressed greater trust in Facebook than MySpace users did in MySpace and thus were more willing to share information on the site" (boyd & Ellison, 2008, p. 222). This trust could explain why Facebook is the fastest growing SNS and more people integrate it into their everyday life. Users have the options of how to communicate with one another; private messaging, *wall* posts, chat and video call. The privacy settings can be easily changed by the users to allow different people to see different parts of their profile (the basic privacy settings are "only friends", "friends of friends", and "public"). A study found that 55% of teenagers had Facebook profiles, 66% of them reported that their profile was not visible to all internet users (Lenhart & Madden, 2007). Thus, users have total control over who can see their *wall* post or others' *wall* post. Users can post notes on their friends' *wall*, comment on, 'Like' the posts of their friends and share others' posts. Users can also participate in conversations which usually occur within the comment sections of other people. In addition,

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users can ask to join various *Groups* on Facebook from the admins of the *Groups*, or some are required to be invited to join a *Group*. The setting of a *Group* can either be *Public* or *Closed* in which *Public* refers to the visibility of the *Group* to its members and the public, while *Closed* can only be viewed by its members. Once a user becomes a member of a *Group*, they can post a status to the *wall*, respond to a post on the *wall* by clicking the 'Like' button to indicate support to a message. They can also write opinions to a post using the 'Comment' function and share their opinions with specific online friends, groups, or the public, or click the Share button to link to a third party site (Wilson et al., 2012). These are some of the features on Facebook that are not found in other SNSs which make it a popular choice among SNS users.

Facebook offers various communication features: written language and language softeners to its users such as profile name and picture, status updates, timeline, emoticons and feelings, places check-ins and Like, Share and Comment. It also enables synchronous and asynchronous communication to take place simultaneously. Users have the choice to disclose their real identities or create different ones on Facebook and this includes using their real pictures/photos or avatars. Avatars are commonly used to reflect the users' physical appearance accurately, in dating pages/sites, for example, avatars are made for users to look more attractive, while they are usually created to make the users look more intellectual in gaming (Vasalou & Joinson, 2009). Users also have the freedom to control how they presented themselves (commonly known as self-presentation) on Facebook in which may be different from the real world. The concept of self-presentation proposed by Leary (1995) can be applied to the Facebook setting in which it reflects how its users attempt to control the impressions and perceptions that others may form of them. This is because SNSs users have total control over creating and maintaining their online image in order to impress potential partners or audiences (Ellison, Heino, & Gibbs, 2006). A study by Mehdizadeh (2010) found that SNS users posted specific photos and revised text in

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functions such as About Me, Status Updates, and Notes for the purpose of self-promotion and to construct preferable online images. For image information control affordance, Facebook contains features such as the *profile picture* and *About me/Basic personal information* in which users have total control. Therefore, the online image that users portray themselves on Facebook may or may not be a true presentation of themselves in the real world or offline.

Some researchers suggested that editing online image is a vital component of online communication to conjure a positive image (Whitty, 2002; Whitty & Gavin, 2001). This, however, opens up to possibilities of individuals illustrating different online images from their offline selves (boyd & Marwick, 2011) for various reasons such as privacy, or even malicious intention (Huberty, 2015). This claim is dismissed by Zywicki and Danowski (2008) who suggested that Facebook users may not be trying to manage their image but rather simply expressing more of their true selves as they were able to do this more precisely and truthfully over the internet than face-to-face (McKenna et al., 2002). This may be very useful for parents/carers of children with disabilities as they were able to share their predicament freely over Facebook rather than face-to-face. Thus, online self-presentation on social media can be both benefitting and damaging, depending on the intentions of the users.

The various content disclosed on an individual's Facebook page may have great implications for how others may perceive, judge, and treat him or her. Due to this, previous studies (Back et al., 2010; Evans, Gosling, & Carroll, 2008; Kim & Lee, 2011) had revealed that users engaged in several types of selective self-presentation activities or strategies when interacting in computer-mediated communication environments, particularly social media such as Facebook. The first strategy is users took special care when constructing message or status expressions by editing, revising or abandoning their ideas until they created acceptable and pleasing impressions in order to communicate effectively (Henderson & Gilding, 2004; Walther, 1996a; Walther, 2006). Using politeness, expressions such as an

admission of impingement, and asking for forgiveness were also being practised by the social media users (Duthler, 2006). Users were more aware of their expression when using social media to ensure a satisfying relationship (Walther, 1996a, 2007). This is evident when they were more satisfied disclosing sensitive information to online support groups which had weaker ties (more distant friends rather than family members or close friends) due to the lowered interpersonal risk and the advantages of obtaining more diverse information about a problem/issue (Wright, Banas, et al., 2010; Wright & Miller, 2010). Weaker ties tend to be more heterogeneous than stronger ties which clearly clarified the intensity of information being disclosed and shared by individuals of an online community. Post, Comment and Like are examples of Facebook features for this expressive information control affordances (Kuo, Tseng, Tseng, & Lin, 2013). Apart from expression control, the privacy of information was also paramount in social media as users highly valued hiding information in certain circumstances (Sheehan, 2002) to minimise embarrassing or private aspects (Lea & Spears, 1992; Tidwell & Walther, 2002; Walther, 1993, 1996a). As Facebook users were susceptible to constant public scrutiny (Muise, Christofides, & Desmarais, 2009), they might selectively control the information to be disclosed so that it minimised the negative impressions other people might have on them (Kuo et al., 2013). Users have control over the audience who can view their postings on the Facebook wall but they have no control over third party use of their postings. Numerous studies had been conducted on information disclosure and privacy on SNSs including a study by McCullagh (2008) which found that users controlled their personal information that could identify them, such as financial or health status, political beliefs and religious views, in order to protect themselves from the over-reaching social control of others and to avoid being judged. To regulate the privacy information control, Facebook prepares features such as the chat room for synchronous interactions (through private messaging) and the post with privacy setting (allow the post to be viewed only by Friends, Public or others). Therefore, expressive information control, privacy information

control, and image information control are three types of information control which are crucial to people's impression management (Feaster, 2010; Leary, 1995; O'Sullivan, 2000).

The Like button is the engine or heart of Facebook and it is the most recognised and used symbol as it attracted 1.6 billion Facebook users to click on it more than 6 billion times a day, surpassing the number of people who conduct searches on Google (Frier, 2016). The users' responses by clicking the Like function can be used as crucial metrics for measuring the effectiveness of online events (Ellison et al., 2007) for fan pages, brands, publishers, and individuals who constantly, and strategically, share the things they think will get the most likes. The Like button is a new method of communication online, which could be parallel to the face-to-face, non-verbal sign of thumbs up, which simply makes interactions easier; just click Like on someone's post, for example, about their new job or newborn, instead of being the 15th person to say congratulations (Frier, 2016). Various studies on the effect of the Like function in Facebook have been carried out in different areas including celebrity fan pages, popular brands of merchandise and library pages. Clicking on the Like button, with a significant number of Likes and comments posted on specific content on the Facebook page provided solid evidence of users' engagement with the fan pages (Glazer, 2012). This feature of Facebook has been used as indicators of users' engagement, their interests and the extent to which the Facebook pages could be further improved or sustained to gauge the present number of users and attract new ones. Initially, the alternative Dislike button was rejected on the basis that it would propagate too much negativity (Frier, 2016), but its counterpart had indeed sparked damaging psychological impact on the users. Apart from the Like button, anecdotes or narratives are also the indications of how a Facebook page could have an impact on its users as highlighted by Glazer's study (2012) in which anecdotes/narratives posted by users on a library page reflected their engagement.

As highlighted earlier, the Like button could lead to the users' damaging psychological impact. Well-being has been a reference for users' psychological impact and

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many studies have investigated the impact of internet use on it. Facebook, being the most widely used online social network, has also been explored in terms of its impact on the users' well-being. A study on college students' use of Facebook in the University of Michigan indicated that prolonged use of Facebook resulted in negative shifts in their well-being, both on day-to-day basis and satisfaction over their life, as they became unhappy and their life satisfaction declined (Kross et al., 2013). Rather than enhancing the users' well-being, Facebook is predicted to be undermining and damaging it. Similar findings had been reported by other studies (Chou & Edge, 2012; Huang, 2010) which also include effects such as interference with physical activity, which had cognitive and emotional replenishing effects (Kaplan & Berman, 2010), and triggering damaging social comparisons (Chou & Edge, 2012; Haferkamp & Kramer, 2011). These effects could indicate that there is a strong connection between the excessive use of Facebook with the decline of its users' affective well-being. If harmful social comparisons explain how Facebook use leads to the decline of users' affective well-being, it is possible that interacting with other people on Facebook either enhances the frequency of such comparisons or magnifies the users' emotional impact (Kross et al., 2013). Making a social comparison of the users' own life to those of others might result in a decline of the former's well-being, especially when the former did not possess or achieve what the latter had. On the contrary, research had revealed positive associations between online social network use (in particular Facebook) and well-being (Valenzuela, Park, & Kee, 2009b). The findings of whether Facebook enhances or reduces individuals' well-being may be more nuanced and potentially influenced by other contributing factors including number of Facebook friends, perceived supportiveness of one's online network, depressive symptomatology, loneliness, and self-esteem (Forest & Wood, 2012; Kim, LaRose, & Peng, 2009; Manago, Taylor, & Greenfield, 2012). Hence, to determine if Facebook is a boon or a bane, it depends on how users make use of the features

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that Facebook offers. The attitude and behaviour that users bring into Facebook when using the online platform are also factors influencing their well-being.

Another advantage of conducting research on Facebook is it allows for the study of people's online behaviour. Facebook profiles can be said to illustrate a user's identity, and the fact that people can judge each other's personality based on Facebook profiles implies two things: "an individual's personality was manifested on their Facebook profile, and some aspects of Facebook profiles were used by people to judge others' personalities" (Bachrach, Kosinski, Graepel, Kohli, & Stillwell, 2012, p. 25). This is further supported by the claim that there was a broad assumption, supported by content analysis, that social network profiles were used to create and communicate idealised selves (Manago, Graham, Greenfield, & Salimkhan, 2008). Facebook users tend to be anonymous by using an avatar as their profile so that the impact of social norms on the users could be diminished (Rolland & Parmentier, 2013). This contradicted the findings in other studies that those who always contribute to the online communities were members who were successful with their behaviour change and yet their profiles still remain anonymous (Cobb et al., 2010; Maloney-Krichmar & Preece, 2005). This is further supported by past research which highlighted anonymity is an advantage of joining an online community support group as members, particularly those who are disabled, need not disclose themselves to others due to being ashamed or having low self-esteem (VanLear et al., 2005). In addition, the information that the users disclose online, the status updates and comments made to others may all be the indications of their online behaviour, although there were claims that individuals illustrated different online identities from their offline selves (boyd & Marwick, 2011). However, creating idealized identities should be hard to accomplish because (a) online social network (OSN) profiles include information about one's reputation that is difficult to control (e.g., wall posts) and (b) friends provide accountability and subtle feedback on one's profile (Back et al., 2010). The result of Back et al. (2010) study suggested that "people were not using



their OSN profiles to promote an idealized virtual identity; instead, OSNs might be an efficient medium for expressing and communicating real personality, which may help explain the popularity of Facebook” (Back et al., 2010, p. 374). Thus, this indicates that Facebook could serve as a platform for the idealised personality that users may not have in real life or indeed a realistic personality that is transferred into the online setting.

### **2.3.3 Research on Facebook in multidisciplinary areas**

The study on Facebook users does not only focus on the sociology but also multidisciplinary areas. Hewitt and Forte (2006) studied students’ feeling of having their professors as Facebook friends, while Mazer, Murphy, and Simonds (2007) researched the effects of faculty participation on teacher-student relations in college. This shows that Facebook is a subject worth studying as “its revolution was significant to both business scholars, who envisioned many innovative opportunities for marketing and research, and social scientists, who viewed platforms like Facebook as a whole new environment that provided multiple methods of social interaction” (Kuo et al., 2013, p. 635). Although Facebook offers a myriad of uses, the interaction that takes place may be harmful to its users, especially the minors. As more users engage with Facebook, the US government passed a legislation banning minors from accessing SNSs in libraries, but a study on librarians revealed that they were against the notion and monitoring those minors was not within their scope of duty (Charnigo & Barnett-Ellis, 2007). The research on Facebook users should not only be limited to the educational setting as the rise of SNSs, in general, indicates a change in the online communities’ group. SNSs are now not only organised around people but also those who share the same interests. As research around SNS’s is rapidly changing, “scholars still have a limited understanding of who is and who is not using these sites, why, and for what purposes, especially outside the US and such questions will require large-scale quantitative and qualitative research” (boyd & Ellison, 2008, p. 224). Therefore, an

ethnographic research on populations outside of the US is crucial in assisting scholars to understand the long-term implications of this tool.

### **2.4 Conclusion**

This chapter explored the literature specifying theories and concepts of social support, communication and Facebook in relation to ASD. The history of each concept as well as the relevant past research was discussed. Issues and limitations in the past research were highlighted to provide a clear picture on the importance of this study to be conducted. This chapter had provided a background/foundation as the theories and concepts were used to determine the methodology for this study. This study provided an in-depth discussion to see whether the theories cited and quoted could be applied to the Malaysian context, which would be deliberated in the discussion chapter. Thus, the next chapter will look into the methodology involved in this study. Data collection method involved two stages, quantitative and qualitative data were explained. Methods and tools for the data analysis, including thematic analysis, grounded theory analysis, discourse analysis, and the use of NVivo software were also described. This was followed by reporting of the research findings, and lastly the discussion of the validity and reliability of this study.

## CHAPTER 3: METHODOLOGY

### 3.0 Introduction

This chapter described the research approach and the discussion of the data collection stages. It outlined the methodology principles of the study which adopted a qualitative method approach to research. Participant observation, archived Facebook data and semi-structured interviews were data collection methods used in this study. The NVivo software was utilised for all data collection and data analysis. Quantitative analysis was conducted on the participant observation data. Thematic analysis and discourse analysis were used to analyse archived Facebook data made by participants to the Autisme Malaysia (AM) Facebook (FB) support group *wall*, and grounded theory analysis was used to analyse the semi-structured interviews. The reporting of the research findings was also explained, and lastly, the validity and reliability of this study were discussed.

The research paradigm for this study was social constructivism. It was assumed that the social supports were embedded within the complex structure of the online society/group and that individuals within that society/group rationalised their position by considering their relationships within it as well as the wider environment outside the online setting.

### 3.1 Research approach

This study adopted a qualitative method research paradigm which used qualitative methods to collect and analyse data. It comprised two data sets, archived Facebook data and semi-structured interviews. The archived Facebook data was used for participant observation which adopted a quantitative method (looking for frequency of activities being carried out on AM FB) and later thematic analysis was conducted on the same Facebook data to look for emerging themes. The reasons for archiving the Facebook data (postings made by

participants) was due to the fact that Facebook allowed for older status to be edited and re-uploaded to the Facebook *wall* and 'Comments' to be removed by the *poster* or the users whose post was commented by the *poster*. These changes which could be made by the participants of this study could affect the analysis of the Facebook data, thus, the approach of archiving these data was considered appropriate.

The semi-structured interviews adopted a grounded theory analysis as it provided more in-depth understanding of the emerging themes occurring in the participants' talk. These two data sets were then analysed for the purpose of data triangulation (Creswell, 2013). As research on Facebook could still be considered as a new research area to study human behaviour and communication, it allowed for various research methods and approaches to be conducted to meet the intended research purposes.

### **3.1.1 Netnography**

The term netnography was first introduced by Kozinets (1998) to illustrate the methodology of ethnography which was carried out online. Other scholars used different terminologies including 'virtual ethnography' (Hine, 2000) to refer to the same methodology. The term was first used as an interpretive method to investigate consumer behaviour and culture on the internet (Kozinets, 1998) as derived from consumer research, cultural anthropology and cultural studies. It included fieldwork and textual account from the online sites. Hine (2000), on the other hand, regarded the internet as a cultural artefact when she included not just internet but other media such as television, radio and newspaper in investigating support sites on the internet in the Louise Woodward court case. Netnography had been used in various disciplines such as marketing, management, business, economics, sociology and information systems (Bengry-Howell, Wiles, Nind, & Crow, 2011). As this study investigated the support groups that exist entirely online using Facebook as a platform, netnography was the most suitable method to be adopted. Similar to traditional ethnography,

netnography also included methods of participant observation and interviews. Researchers could choose to carry out 'pure ethnography', 'pure netnography' or 'blended netnography' (Kozinets, 2010).

### ***Blended Netnography***

This study adopted a blended netnography approach which combined both online and face-to-face data collection. As the Facebook support group "extends beyond the online community context into the larger social world" (Kozinets, 2010, p. 67), blended netnography would be the most suitable approach to gain the complete picture and understand the lived experience of these parents of a child with ASD. The Facebook data alone was not sufficient to answer the research questions and thus face-to-face semi-structured interviews were conducted. The semi-structured interviews gave a more in-depth understanding of the lived experience of these parents which might not be illustrated on the Facebook support group wall. The reason for implementing the face-to-face interviews rather than online interviews was the constraint these parents had if the latter was to be adopted. A weak internet connection might hinder the interviews if they were conducted online. In addition, online data complemented the understanding of ethnographic research or vice-versa, thus the need for blended netnography/ethnography (Garcia, Standlee, Bechkoff, & Cui, 2009). Therefore, blended netnography was adopted for this study.

### ***Defining the field in netnography***

Geographical location of a community assisted in defining the field boundary in ethnography. In netnography, a website, an online forum or a bulletin board became the field as an online community was made up of limitless geographical locations. For this study, the Autisme Malaysia's Facebook group (AM FB) was a single-site online community dedicated to parents of a child with ASD and the members resembled a single-geographical location, which is Malaysia. Although the Facebook group could be accessed by others outside of Malaysia, users did need to 'request' to be added as a member. However, it could

be said that almost 99% of the members in AM FB group are Malaysians as they shared the same language of communication (Malay), practices and activities. Thus, deciding AM FB group as the 'field' gave an accurate picture of this online community.

Traditional ethnography required the researcher to 'enter' the field to carry out participant observation to observe the activities carried out by the samples, and once the observation was completed, the researcher 'left' the field. "In netnography, as there was no 'physical field', 'entering the field' meant 'starting to engage in the community's activities' rather than logging in to an online site, while 'leaving the field' referred to 'disengagement with these activities'" (Kulavuz-Onal & Vásquez, 2013, p. 228). In this study, after the researcher obtained permission from the admin, the researcher first 'entered' AM FMs group as a *lurker*. *Lurker* is defined as someone who joined an online community but did not participate actively, merely observing what was happening in the group and remaining silent (Preece, 2000). The activities that the researcher carried out were mainly scrolling the AM FB wall and reading members' status without jotting down any observational data. The reason for this was to get an idea of what topics parents discussed on the AM FB group. When consent had been obtained at a later stage from the participants of the study, the researcher 'entered' the field as a participant.

### ***Participation in Facebook for participant observation***

The concept of extended observation of the culture-sharing community, usually through participant observation, is a process of establishing a rapport that necessitates the researcher to immerse and blend into daily lives of the community being observed (Atkinson & Hammersley, 1998; Creswell, 2013). Then, the researcher removes herself from the community to engage in the data to comprehend what is going on and enable her to write about it (Bernard, 1994). Participant observation was crucial in traditional ethnography and this main method of fieldwork was also adopted in netnography. The difference between these two was that participant observation in netnography took place entirely online through

computer-mediated technologies “to arrive at the ethnographic understanding and representation of a cultural or communal phenomenon” (Kozinets, 2010, p. 89). There are varying levels of participant observation: nonparticipant (when researcher learns about a culture without ‘entering’ the field, such as through archived documents and media), passive participation (researcher ‘enters’ the field physically, observing without having interactions with the participants), and active participation (researcher ‘enters’ the field and engage and involve actively with the community) (DeWalt & DeWalt, 2002). In this study, the researcher adopted passive participation then changed to active participation.

In netnography, in this study particularly, after obtaining consent from the participants, the researcher started off as a passive participant. She entered the field (AM FB) as a member after identifying herself as a researcher and observed the activities without having any interaction. At this stage, only the participants of the study were aware of her presence and her observation of the participants’ activities on the AM FB *wall*. At a later stage, her role changed into active participation when she engaged actively in the community by clicking ‘Like’ button, ‘Share’-ing articles related to ASD, and ‘Comment’ on participants’ status. This allowed the researcher to immerse in the everyday activities of these parents on AM FB.

### ***Observational data vs. Archived data in netnography***

In traditional ethnography, recording observational data (in the form of observational sheet/form, field notes/audio recording) was straightforward as the researcher entered the community and carried out the observation. In netnography, however, the observational data was a blurry term as most data available online was archived (Kulavuz-Onal & Vásquez, 2013). Most computer-mediated communication activities involved mainly textual data (webpages, bulletin board, Facebook), which were archived. Thus, observation in this context involved “watching text and images on a computer screen” (Garcia et al., 2009, p.

58) and ‘reading’ extensively and making meaning of textual communication (Kulavuz-Onal & Vásquez, 2013).

One of the reasons why Facebook was a rich data source is it left traces of activities conducted by its users. Not only did participants not need to recall the activities they conducted on Facebook, the ease of accessing and analysing large amounts of archived texts have a significant prospective for direct observation (Seale, J., MacFarlane, & McPherson, 2010). Most postings (Status, Like, Comment, Share) were archived in the Facebook *wall* for all personal, page or group Facebook accounts. Due to the ambiguity of observational data *vs.* archived data in netnography, in this study the researcher collected all the archived Facebook postings made by the participants from 1<sup>st</sup> July 2014 to 31<sup>st</sup> Aug 2014, and ‘observed’ them by reading extensively, making meaning of the status and comments, and noting down the field notes in the observational sheet. The ‘physical’ observation was carried out for the activities conducted on AM Facebook *wall* from 1<sup>st</sup> Sept to 30<sup>th</sup> Sept 2014 as at this time ethics had been approved and consent had been obtained from the participants. During this period, observational data was recorded in the observational sheet. All postings made in September that were directly ‘observed’, were archived for further coding and analysis. One important thing to note was that all activities which were archived on the Facebook *wall* could be edited by the users at any time. This required the researcher to be constantly ‘observing’ the AM Facebook *wall* even after the three-month period of data collection. The observation ended in December 2014 which allowed for three months of ‘edited’ activities to be observed.

### ***Challenges of using Facebook as data sources***

Despite the description of the approach adopted for this study, as explained earlier, there were some challenges related to using Facebook as a data source. First, the privacy setting of the Facebook group being investigated determined whether the group could only be viewed, commented, liked or the content shared. At the beginning of this study in 2013,



Autisme Malaysia started off as a *Closed Group* which required a Facebook user to become a member enabling the user to view the AM FB *wall*. Thus, the researcher had to request to join the group and later the admin of the group approved the request which allowed the researcher to conduct activities on the *wall* apart from viewing and reading postings. While the research was being conducted, the admin changed the setting of the group to a *Public Group*. This change, however, did not have any effect on this study. It only meant that other users (who were not members of the AM FB group) were now able to view and read all the postings on AM FB wall, 'Like' and 'Share', but they were unable to post a comment.

Second, the call for participant recruitment, which was posted to the AM FB *wall*, easily became an 'old post' and was missed by the AM FB members due to the active and numerous postings of statuses by the members. There was an average of ten postings (status) a day including numerous comments from members which made the *wall* quite crowded with text, visuals and audio recordings. Thus, the call for participants had to be reposted to the *wall* twice.

### **3.2 Data collection**

This study involved two stages of data collection, the activities conducted by participants in the Autisme Malaysia's (AM) Facebook (FB) support group page, and an interview. Twelve participants who were members of AM FB group were recruited as samples. The following section describes the sample size, participant recruitment and both data collection stages.

#### **3.2.1 Sample size**

Theoretical saturation was the definitive criterion to determine sample size in a study using the grounded theory approach. Data was saturated when no new theme or category emerged and the relationships among themes or categories were well established and

validated (Strauss & Corbin, 1998). Twelve was a sufficient number for data saturation as saturation of themes could emerge with 8 interviews (McCracken, 1988). Interviews were analysed to determine the necessity for additional sampling but the depth of data with no new emerging themes/categories identified in the last two interviews had indicated that data was saturated. Therefore, the data collection was completed with only 12 participants.

### **3.2.2 Participant recruitment**

The AM FB support group page was set up in 2011 by Zamri Tembol who also acted as the administrator of the AM FB page. Having a child with ASD had inspired him to set up the FB page which had become the medium of communication for parents in Malaysia who have a child with Autism Spectrum Disorder (ASD). Those who wanted to join the AM FB group had to seek approval from the administrator or be invited by other members who had joined the group. Apart from this, any activities that took place in the AM FB page were being monitored by the administrator in ensuring that all members adhere by the rules and regulations that had been laid out.

Having a family member who was disabled had motivated the researcher to become a member of the AM FB group in early 2013. The initial intention of becoming a member was purely educational, to learn more about ASD. During this period, as a member, the researcher remained as a *lurker*, reading other members' post and comments. However, the interest in conducting a research on this group was inspired after noticing how active the group was, indicated by the number of members joining the group and the communication that took place on AM FB. For the purpose of this study, approval to conduct the research was requested and had been obtained from the administrator through a formal letter sent through e-mail (see Appendix 2).

After the approval was given by the admin, an announcement was made by posting a status to the AM FB group inviting members to participate in the study. Brief information

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stating the purpose of the study was included in the status. Members, who were voluntarily interested in becoming the participants, could either leave a comment on the status, contact the researcher through an e-mail address given or send a private message through researcher's FB page. All of these members contacted the researcher through private message on the researcher's FB page (there was no requirement for the participants to become 'friend' with the researcher in order to send a private message through FB). Thus, private messages through FB became the medium of communication between the participants and researcher as the former preferred such medium. The researcher explained thoroughly about the study, what was required of the participants and other relevant details including participants giving verbal consent to participate in the study before signing the consent form. Then, they were given the information sheet to read and decide (if they wanted to participate in the study) and to return it in a week's time. The first 12 members who had signed and returned the consent form electronically were recruited for the study. The participants also indicated the possible date, time and place for the interview in their consent form.

The 12 participants were members originated from different parts of Malaysia, namely from the north (Kedah and Pulau Pinang), east (Terengganu and Pahang), central (Selangor and Kuala Lumpur) and south (Johor). It included both female and male, as participants. In order to remain anonymous, these participants were given a code: 001 to 012. Table 3.1 below showed the demographic data of the participants.

Table 3.1.

### *Demographic Data of the Participants*

Participants	Gender	Number of years joining AM FB support group	Employment status
Participant 001	Female	5 years	Unemployed/Housewife

Participant 002	Female	4 years	Working
Participant 003	Male	5 years	Working
Participant 004	Female	4 years	Unemployed/Housewife
Participant 005	Male	5 years	Working
Participant 006	Female	1 year	Working
Participant 007	Female	1 year	Working
Participant 008	Female	4 years	Blogger/Housewife
Participant 009	Female	3 years	Self-employed
Participant 010	Female	2 years	Unemployed/Housewife
Participant 011	Female	1 year	Unemployed/Housewife
Participant 012	Female	1 year	Unemployed/Housewife

### 3.2.3 Data collection methods

#### i. *Archived Facebook data*

##### Participant observation

Archived data from the AM Facebook *wall* was collected from 1<sup>st</sup> July 2014 to 30<sup>th</sup> Sept 2014. All postings including Status, Like, Comment and Share made by the participants were copied using Greenshot software into Word docs and saved as PDF. It was then imported into NVivo and each participant was given a code according to the previous code in the demographic data. After all the postings had been transferred and saved in NVivo, participant observation was conducted to identify participants' communication pattern in AM FB. The communication pattern included communication activities and frequency of such activities (He, Butler, & King, 2007). Further details on the description of activities were considered as the researcher's field note. Table 3.2 showed the participant observation checklist which was adapted from user activities in Orkut, a social networking site mostly used in Brazil (Benevenuto et al., 2009).

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Table 3.2.

### *Checklist for Communication Pattern Performed on AM FB Support Group*

Month	Week	Participant	Categories	Description of activities	Frequency	Descriptions
July 2014	Week 1	001	Posting (text)	<ul style="list-style-type: none"> <li>Post status</li> </ul>		<i>e.g.</i> <i>Positive/</i> <i>negative</i> <i>encouraging/</i> <i>discouraging</i> <i>comment</i>
			Photos	<ul style="list-style-type: none"> <li>Post photos</li> </ul>		
			Likes	<ul style="list-style-type: none"> <li>Like others' postings/photos</li> </ul>		
			Comment	<ul style="list-style-type: none"> <li>Comment own posting</li> <li>Comment others' postings</li> </ul>		
			Share	<ul style="list-style-type: none"> <li>Share links</li> <li>Share others' postings</li> </ul>		

This quantitative data was vital in showing the participants' engagement with the AM FB group. The frequency of activities conducted indicated their engagement and the features of Facebook that they frequently utilised. The descriptions of the activities further assisted the researcher in understanding the types of communication these participants engaged in. All these helped the researcher to design the interview questions and later validate and triangulate the findings from the thematic analysis and semi-structured interview. Hence, this small quantitative method was adopted in this study.

### Thematic analysis

Using the same archived Facebook data, qualitative analysis of emerging themes was conducted. Pre-empted themes associated with social support concepts/dimensions as proposed by social support theorists were used as a basis for the analysis. There were ten concepts/dimensions used at the beginning of data analysis. These ten concepts/dimensions were further grouped into larger social support concepts/dimensions particularly those which had similar meanings and this yielded a smaller number of concepts/dimensions. Emerging new themes were later recorded as new categories. These categories were later used when analysing semi-structured interviews.

#### *ii. Semi-structured interview*

The second stage of data collection involved semi-structured interviews. As described earlier, this study adopted blended netnography which comprised face-to-face semi-structured interviews. All 12 participants were asked if they were willing to participate in an interview when they were being briefed about the study. Their participation in the interview further elaborated their experiences in using AM Facebook support group and the data later used to complement the data findings in the first stage, participant observation and thematic analysis of the archived Facebook data.

A semi-structured interview was more manageable than a structured interview and allowed for flexibility (Hammond & Wellington, 2013) to include more questions to further understand the participants' experience. It was an invaluable tool for understanding human behaviour which assisted researchers to understand *why* people do such things and the lived experience of other people (Hammond & Wellington, 2013; Seidman, 2006). "Every word that people use in telling their stories is a microcosm of their consciousness" (Vygotsky, 1987, pp. 236-237). This was applied in this study as both the stories the parents wrote on the AM FB wall and spoke in the interviews made them conscious of their lived experiences. "Individuals' consciousness provides access to the most complicated social and educational

issues, which are considered abstractions based on the concrete experience of people and this can be achieved through the use of language during an interview” (Seidman, 2006, p. 8). A basic assumption in interviewing research was that “the meaning people make of their experience affects the way they carry out that experience” (Blumer, 1969, p. 2). Thus, not only would face-to-face semi-structured interview give an insight on the participants’ experience in using the AM FB page as a tool for support group, it also “nuances and enhances a study of their social world by revealing aspects of it that are not captured” (Kozinets, 2010, p. 110) in their Facebook status alone. The participants in this study were able to share experiences such as why they behaved in such a way online and how they predicted others’ views on them during the interview which could not be captured through ‘observing’ their activities on AM FB group.

The researcher designed the interview questions (see Appendix 6) as guidance after the first stage of data collection (archived Facebook data). The questions were based on the research objectives of the study, research questions and also participant observation made by the researcher on the activities conducted in the AM FB group. More questions were added during the interviews based on the responses given by the participants.

### **3.3 Data Analysis**

#### **3.3.1 Archived Facebook data**

Archived Facebook data involved two stages of analysis; quantitative analysis and qualitative analysis, which comprised thematic analysis. For quantitative analysis, Microsoft Excel was used to design the observational sheet which was used to record activities conducted by the participants on the AM FB *wall*. Frequency count was conducted to analyse this observational data. For the purpose of qualitative analysis, NVivo software was used to gather the archived data and carry out the analysis.

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### Stage 1: Quantitative analysis

Using the checklist as illustrated in Table 1.3, the communication pattern of activities conducted and their frequencies on AM FB support group were first quantified. This was done using Microsoft Excel. The communication pattern indicated participants' behaviour in using AM FB support group. The findings were used to complement the findings from the thematic analysis of the archived Facebook data.

### Stage 2: Thematic analysis

Archived Facebook data particularly textual postings (participants' status and comments) illustrated communication content, particularly information-exchanged behaviours of the participants (Mesmer-Magnus, Leslie A. DeChurch, Jimenez-Rodriguez, Wildman, & Shuffler, 2011). These archived Facebook data involved two types of analysis, which were thematic analysis and discourse analysis. The thematic analysis was aimed to identify the pattern of the content of the postings (status and comment) made by the participants while discourse analysis revealed the dominant discourse in the textual Facebook data. Thematic analysis consisted of a more systematic characteristic of content analysis which allowed the researcher to make meaning in the context of those themes resulting in the refinement and complexity of a strict qualitative analysis (Marks & Yardley, 2004). The themes came both from the data (inductive approach) and prior theoretical framework of the phenomenon being studied (deductive approach) (Bernard & Ryan, 2010). Based on the social support concepts/dimensions that made up the theoretical framework of the study (Barrera, 1986; Cohen & Hoberman, 1983; Sarason, Levine, Basham, & Sarason, 1983), data in this study was coded using these themes. Themes were also generated based on the research questions of the study including the purpose of the postings. Other new themes emerged from the data were coded as well.



### Stage 3: Discourse analysis

The final process for the data analysis for the archived Facebook data involved discourse analysis to identify the dominant discourse which was pertinent in the Facebook communication among these parents. The recurring discourse informed the researcher of the discourse pattern that dominated the communication that took place in the AM FB support group. Facebook was a useful avenue to look at the discourse as there was a lack of discourse research being carried out on Facebook in comparison to the vast research of discourse on other media such as newspapers, annual reports and speeches. Analysing discourse helped the researcher to identify how discourse was used by the participants to build and sustain social reality (Silverman, 2014).

#### **3.3.2 *Semi-structured Interview***

The researcher started off analysing the transcript of the semi-structured interviews using thematic analysis with themes that were derived from the analysis of the archived Facebook data. More themes emerged as the analysis was conducted and the researcher discovered a pattern which had a connection between the themes, for example, a cause-effect relationship. Thus, the researcher decided to adopt a grounded theory analysis. This understanding of the emerging themes.

### Stage 1: Grounded Theory Analysis

The audio-recorded interview was transcribed using NVivo and later analysed using detailed procedures of grounded theory approach. It comprised three phases of coding namely free/open coding, axial coding and selective coding (Corbin & Strauss, 2008). The central phenomenon for the study focussed on social support theory/mechanism. The free/open coding of the transcribed data was based on the thematic analysis carried out earlier with more emerging themes based on the data (inductive approach) and also questions posed during the interview. Further analysis involved axial coding where data was

organised into conditions, actions, consequences and links (Strauss & Corbin, 1998). The final phase of the data analysis involved selective coding in which findings were presented in a figure that explained the theoretical model (a range of conditions and consequences associated with the fundamental phenomenon) (Strauss & Corbin, 1990)

### **3.4 Research findings**

As described earlier, both data sets were analysed accordingly but both findings were then merged to find the common ground and then reported. A figure/non-linear model was drawn in Chapter 4 to illustrate the findings as suggested by Strauss and Corbin (1998) when adopting grounded theory as a method for data analysis. Results and findings were then written based on themes (pre-empted and emerging) as suggested by Becker (2007); (Lindlof & Taylor, 2011). The themes revolved around categories associated with an established theory such as identifiable past social support theory; emotional support, instrumental support, and informational support. These past theories or pre-empted themes gave this writing an organisational structure to lay on top of the data. However, in order to build theory and knowledge, it was important to push the limits of existing structures by borrowing other theories/concepts (Tracy, 2013). In this study, for example, the concept of computer-mediated communication was adopted to illustrate the communicative features, linguistic and paralinguistic features. The addition of this concept extended the current thinking on the social support literature and helped justify why a Facebook support group was effective especially among parents of a child with ASD in Malaysia seeking social support. In short, some of the themes/categories found were based on the existing literature, while new ones emerged from the data analysis.

### **3.5 Validity and reliability of the study**

Validity and reliability are essential in measuring the credibility of findings of a research. Assessing the validity and reliability of study findings requires researchers to “make judgements about the ‘soundness’ of the research in relation to the application and appropriateness of the methods undertaken and the integrity of the final conclusions” (Noble & Smith, 2015, p. 34). There are various contrasting views about the application of tests and measures used to establish the validity and reliability of quantitative research and qualitative research, as the tests and measures seem inappropriate to evaluate the latter (Long & Johnson, 2000; Rolfe, 2006). Therefore, the term credibility of research is frequently used to indicate the validity and reliability in a qualitative study.

There were several strategies used to ensure the credibility of the research findings which had been implemented in this study. First, a qualitative research should include rich and thick verbatim descriptions of participants’ accounts to support findings (Slevin, 2002). This was evident in this study as descriptions of participants’ experiences to support the findings were recorded in various themes in the NVivo software (see Appendix 8-10). The cited participants’ accounts illustrated in this study were minimal due to the limitation of word count of this thesis. Second, the research should demonstrate clarity in terms of thought processes during data analysis and subsequent interpretations (Sandelowski, 1993). In order to ensure clarity, the researcher always checked the data against the pre-empted themes related to the theories that had been reviewed in Chapter 2. A similar approach was used when interpreting the results and findings. Finally, the research should include data triangulation in which different methods of data sources assisted in producing a more inclusive set of findings (Bryman, 2008; Fraser & Greenhalgh, 2001; Kuper, Lingard, & Levinson, 2008; Neuman, 2006).

Triangulation involved multi-site, multi-method and multi-person to enhance the credibility of this study. Evidence from different individuals, types of data, or/and methods

of data collection were substantiated to ensure a valid and reliable research (Creswell, 2013). Although the participants in this study were recruited through the Autisme Malaysia Facebook group, the twelve participants were indeed representing different geographical locations in Malaysia. They resided in the northern, east, south and central of Malaysia and thus the findings could be said to represent the community of different parts of the country. In addition, this research used two data collection methods, archived Facebook data and semi-structured interviews. The combination of different methods and instruments allowed the researcher to gain a more accurate and credible perspective of the phenomena being investigated. The triangulation process allowed the researcher to observe the participants from different perspectives and viewpoints, and thus making the researcher more confident of the observations, interpretations and conclusions made in this study.

### **3.6 Diagram illustrating methodology of the study**

The methodology described and explained previously was illustrated in Figure 3.1 below.

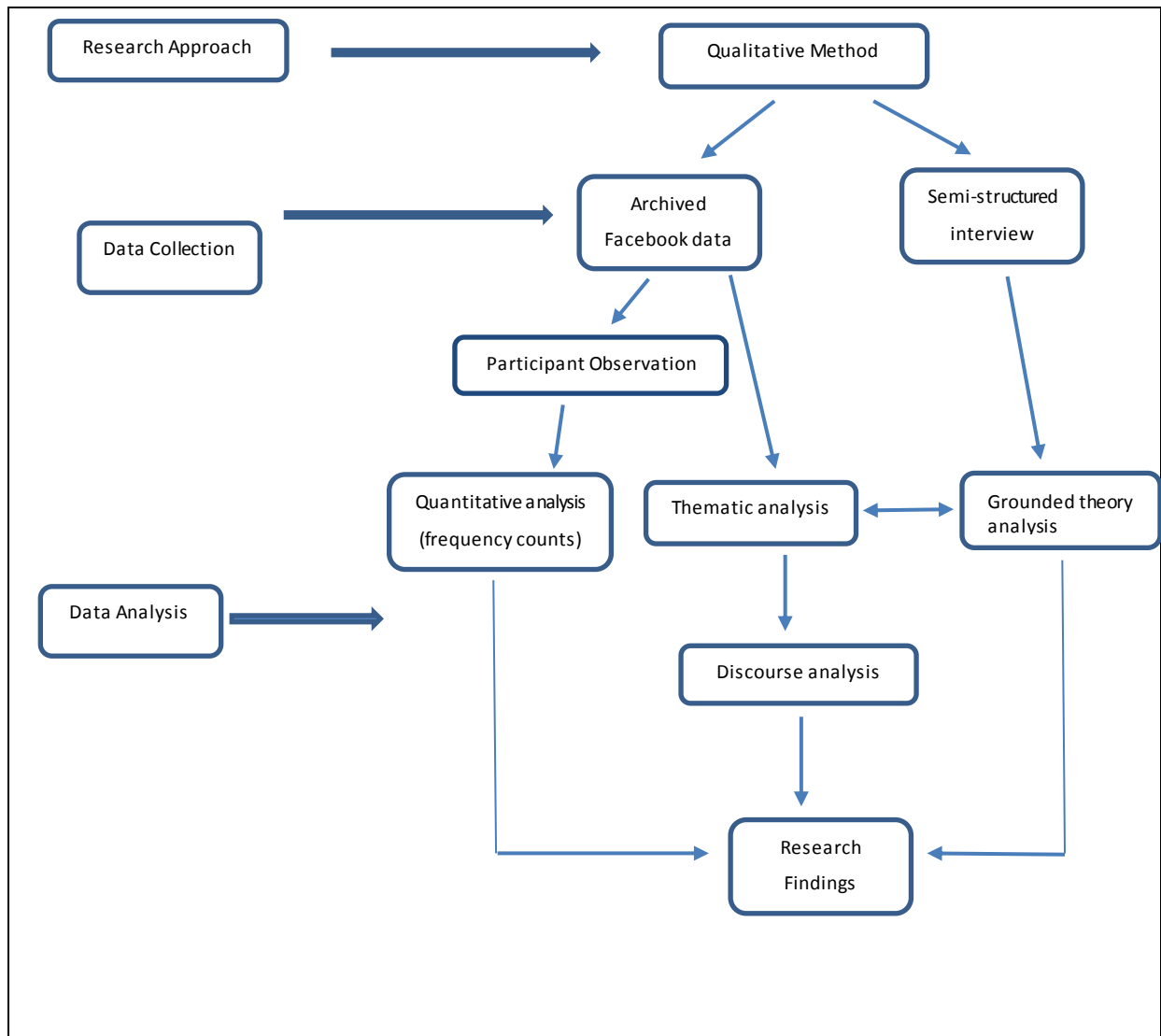


Figure 3.1. Diagram illustrating the methodology adopted in this study

### 3.7 Conclusion

This chapter had illustrated the methodology that was adopted as a direction for this study, including the approach and tools used to carry out data collection and data analysis. A detailed description of the methods and tools used and justifications for using them in this study were also described. The use of blended netnography was one of the strengths of this study as it was a novel approach as “multiple methods and modes were integrated around the core method of observation” (Roller & Lavrakas, 2015, p. 191) as that of conventional ethnography. This chapter also acknowledged that Facebook as a platform for “virtual reality is not a reality separated from other aspects of human action and experience, but

rather a part of it” (Garcia et al., 2009, p. 54). This chapter also provided a linkage between the literature review of the study and the data analysis and findings. It provided a methodological underpinning on which the study was built. The following chapter, Chapter 4, will provide the detailed results and findings based on the analysed participants’ observational data, archived Facebook data and semi-structured interviews.

## CHAPTER 4: RESULTS AND FINDINGS

### 4.0 Introduction

This chapter presented the results and findings of this study. This chapter was written based on the analysed data from the (i) participant observation, (ii) archived Facebook data and semi-structured interview. Results from the participant observation illustrated the frequency of activities conducted on the AM FB *wall* by the participants in this study. It could be encapsulated that most participants who had been members of the group for three years or more conducted activities more frequently, particularly posting of statuses on the *wall*, which was an indication of their high level of engagement with the support group.

The results from the archived Facebook data and semi-structured interviews were discussed simultaneously as both data complemented each other and they offered a means of triangulating the data. The findings from the qualitative data indicated three major categories, (i) online engagement, (ii) expression of feelings, and (iii) social support. All these three themes were intertwined which led to the positive and negative impacts on the participants. These impacts were also caused by the discursive struggles that participants faced when communicating both synchronously and asynchronously on the AM FB support group. Despite these impacts, participants expressed hope for the sustainability of the Facebook group. All these will be discussed extensively in this chapter.

### 4.1 Results from participant observation

The first method of data collection was participant observation, using a checklist adapted from user activities in Orkut, a social networking site mostly used in Brazil (Benevenuto et al., 2009), and the findings that described the activities conducted by the parents in the AM FB support group were illustrated below. A total of 320 statuses were

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posted to the AM FB *wall* within the 3 month period of observation. The more extensive checklist could be found in Appendix A. The observation was focused on the activities the parents conducted on the AM FB social support group *wall* which was summarised in Table 4.1.

Table 4.1.

### *Summary Findings of Participant Observation*

Participants/ number of years joining AM FB	Posting categories/Frequency (July-Sept 2014)					
	Status posted			Like	Comment	Share
	Textual	Photos	Video			
Participant 001 /5 years	5	3	2	34	34	
Participant 002 /4 years	4	3		113	43	
Participant 003 /5 years	8	12		24	30	4
Participant 004 / 4 years	10	2	-	86	71	
Participant 005 /5 years	26	58	4	89	83	3
Participant 006 / 1 year	5	2		23	23	
Participant 007 / 1 year	5			5	48	
Participant 008 / 4 years	90	61	4	145	193	34
Participant 009 /3 years	12	11		31	57	3
Participant 0010/2 years	12			17	11	
Participant 0011 /1 year	4	5		23	31	3
Participant 0012 /1 year	4			18	15	

It can be deduced from the findings that parents in this study engaged actively in the AM FB support group. The number of statuses posted on the wall varied between the participants with those who had been in the Facebook group more than three years posted status more frequently. They were also highly likely to post comments and click 'Like' for



other parents' statuses. However, this was not the case with Participant 003 who had been in the group for 4 years and yet did not 'Comment' and 'Like' as frequent as other members with the same number of years. The reason could be that Participant 003 was one of the admins, who played his role more as an observer and moderator of the interaction taking place on the wall, hence, posting less for his own purpose. It could also be due to the nature of the participant who is a police officer with irregular working shift limiting the hours to be spent on the AM FB support group.

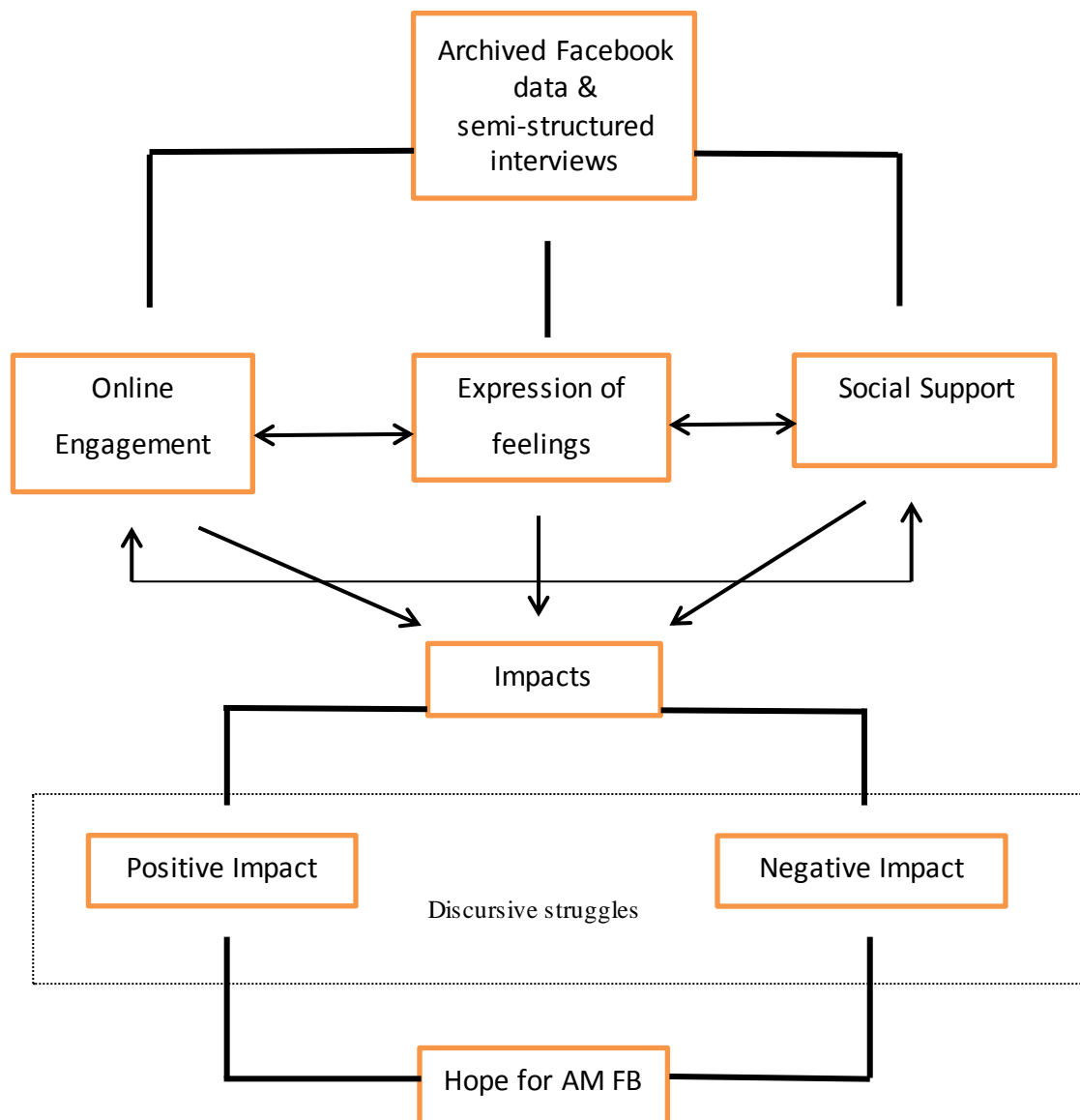
In contrast, parents who had been with the AM FB support group less than three years posted less number of status on the wall but commented more on other parents' statuses. Despite this difference, it could be claimed that parents were highly likely to post a status accompanied by a photo as the numbers for both categories were frequently equal. The reason for such behaviour could be because the purpose of the photo was to illustrate the status (particularly narrative as a status) which further helped others to comprehend what was being narrated and to accentuate the narrative. A similar pattern of activity could be seen with the number of 'Like' and 'Comment' in which it could be said that parents commonly posted a comment on the status accompanied by clicking the 'Like' button. Both activities were carried out at the same time, perhaps as a show of support to the status posted by other parents. One 'Comment' recorded in the checklist referred to either a comment or several comments made to the same status.

Parents in this study seldom posted video and shared others' statuses or secondary sources (such as links and online articles). This could be because posting or uploading a video on Facebook required a large amount of internet data compared to a photo, while sharing secondary sources required parents to spend more time finding sources and reading articles on the internet before sharing them on the AM FB support group. These findings were used to further justify the findings of the archived Facebook data and the semi-structured interviews.

## **4.2 Archived Facebook data and semi-structured interviews**

The process of coding and categorising had been described in the previous chapter. First, the researcher carried out the open coding by grouping the data into appropriate themes. The 28 themes which emerged from the data were labelled accordingly (refer Appendix 9). These themes were later coded into specific categories based on the pre-empted themes as found in the key concepts of social support (refer Table 2.1) and emerging themes which included motivation and attitudes. These 10 categories were then grouped into a more refined categories that resulted in three major findings; online engagement, expression of feelings and social support, that lead to the impacts on the parents and hope for the Facebook group.

Based on the analysis that was carried out as described in the previous chapter, the results and findings were discussed below. Open coding of both the archived Facebook data and the interview revealed 28 themes. Axial coding of these themes was carried out and resulted in 10 categories with relevant sub-headings. The 10 categories were (i) challenges faced by parents, (ii) developing positive attributes, (iii) freedom of expression, (iv) hope and expectations, (v) impact of AM FB, (vi) parents early reactions, (vii) self-driven motivations, (viii) social responsibilities practices, (ix) social support, and (x) things shared on AM FB. The final step was selective coding in which these categories were arranged for further development and refinement. Figure 4.1 below showed the depth and complexity of the results and findings which were both pre-empted and emerging.



*Figure 4.1.* Summary of key findings

The three major categories were online engagement, expression of feelings and social support. Each category had its own sub-themes which were discussed further. As could be seen in the diagram, the connection between the three major findings was not a linear process. All three were connected to each other or complement each other as in online engagement could be a pre-requisite to the expression of feelings and social support and vice-versa. Participants were driven to online engagement as they were able to express their feelings online and seek and obtain social support simultaneously. On another note,

participants who intended to seek social support online would be motivated to search for an online support group, join the group and participate in the online communication.

Expression of feelings became one of the ways they participated in the communication. This later resulted in them becoming engaged with the Facebook group. Similar concepts could be applied to participants who expressed their feelings as a way to seek social support and this showed how they became engaged with the Facebook group. Hence, this showed that all three concepts were connected in which one concept could be the cause or the effect of another concept.

These three concepts contributed to the discursive struggles in which later resulted in both positive and negative impacts on the participants. Discourse analysis of the data identified the concept of discursive struggles within the participants as they communicated synchronously and asynchronously on the AM FB support group. The positive and negative impacts were placed within this concept as the discursive struggles evoked both impacts, for example, participants who struggled with a negative impact of the AM FB group later changed it to a more positive impact after going through the experience of handling and managing the negative impact. It could happen the other way round too. This was further discussed when highlighting the discursive struggles later.

Despite experiencing the discursive struggles, participants in this study expressed hope for the AM FB support group. Although the research question did not address this, the theme of hope emerged from the data and it was worth highlighting in this study as it denoted the future of the AM FB support group in Malaysia and the efficacy of Facebook as a platform for support group which could be adapted by other support groups dealing with other participants.

### **4.2.1 Online engagement**

One of the main findings was online engagement. As the study looked into the use of Facebook as a tool of communication and support, this category was anticipated. However,

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the sub-themes under online engagement helped to further understand why parents engaged in the AM FB (purposes) and what they did on that platform and what did communication on Facebook entail (features). In order for these participants to participate in the online communication, they became part of the online engagement. Online engagement largely involved three main aspects, (i) purpose (why), (ii) activities being conducted online (what), and (iii) features of the online communication (how). The findings of activities conducted on the AM FB support group here were used to support the findings of the activities through the participant observation earlier. Table 4.2 illustrated the sub-themes of online engagement.

Table 4.2.

### *Sub-themes of Online Engagement*

Why (purpose)	What (activities)	How (features)
<ul style="list-style-type: none"><li>• Admin responsibilities</li><li>• Motivation to join AM FB</li><li>• Motivating factors to others</li><li>• Urge to take action</li><li>• Building networking</li></ul>	<ul style="list-style-type: none"><li>• High/Low engagement</li><li>• Sharing as a way to communicate</li><li>• Contents of status<ul style="list-style-type: none"><li>a) challenges parents face</li><li>b) positive improvement of their children</li></ul></li><li>• Building networking (tagging names)</li></ul>	<ul style="list-style-type: none"><li>• 'Like'</li><li>• 'Feeling'</li><li>• 'Share'</li><li>• Language use</li><li>• Private (private message) to Public (Facebook wall)</li><li>• Synchronous vs. Asynchronous</li></ul>

### *Administration responsibilities*

Data from both the interview and the AM FB wall showed that the admin had a huge responsibility in ensuring that members obtained the support they needed by reminding others to respect one another and not create any controversial issue that could cause stress to others. In keeping up with the group's rules, members should be aware before posting any

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comments or status to the AM FB *wall* as their behaviour online was being monitored by the admin. The repercussion of misbehaviour was huge as not only the post or comment would be deleted; the members could be blocked or removed completely from the group. It may sound harsh but the rules were outlined clearly as the aim of the AM FB support group was to offer support to parents of a child with ASD and not to add more pressure and stress to these parents with such heated debate. The admin regularly kept reminding the members about the rules by posting them to the AM FB *wall* particularly when controversial issues occurred, such as vaccination, as depicted in Figure 4.2 and the interview transcript below. Again, the duty of these admins was voluntary, thus members should respect their commitment to the group.

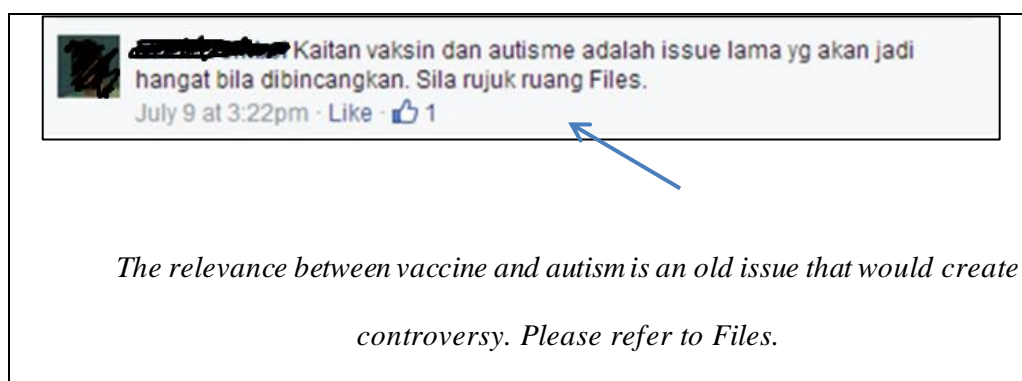


Figure 4.2. Admin's role in dismissing controversial issue.

“When it comes to postings to AM FB *wall*, I play two roles...as an admin and a parent of a child with ASD, for example, the issue of vaccination. There are two contradicting views, one group who is pro-vaccine and the other against-vaccine. So, in this case, we (*admins*) usually take a neutral side. WE don't want parents who are too extreme with their beliefs because there is no cure for autism and no definite causes of autism. Even experts couldn't point out clinical causes to autism! There is none. Thus, we have to highlight that frequently. So what we did was to put notes and information that we had gathered in the Files section in the AM FB support group. When any of this issue arises, we (*admins*) would interfere in the comment thread by asking the parents to refer to the Files section. This will usually subside the heated debate between those two contradicting group. I believe whatever beliefs or views

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that they have, they need to respects others who may have different views from theirs and most importantly respect the group policy”. (ZT)

### *Motivation to join the AM FB group*

The initial purpose of joining this Facebook support group for these participants was to find an avenue for them to seek more information about their child’s ASD condition.

Motivation to join the Autisme Malaysia Facebook support group was closely related to the challenges that these participants had as parents of a child with ASD in Malaysia. One of the reasons was triggered by the nonexistence of local online support groups. This could be seen from the interview transcript,

“...joining Autisme Malaysia is because there is no other online support group based in Malaysia” (MA)

Most of the online support groups were based in other countries, mostly Western countries.

“When I go to Google and type in ‘autism’, the result appears directing to all websites in other countries such as UK, Japan, US and none from Malaysia. That’s why I said to myself that I will create Autisme Malaysia Facebook group. Who knows it might be useful one day”.

(ZT)

This prompted the admin to initiate the AM FB group back in 2011.

“I have a Facebook account but I don’t know where to find the information. When I searched online, I only found a motivational website on autism which is based overseas”.

(NS)

Motivational websites might be helpful for getting emotional support for these participants but that was insufficient. The only support group that could be relied on was a face-to-face support group organised by the hospitals and yet the frequency and mostly a one-way communication was deemed inadequate for these participants.

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“The only support group available is the one organised by the hospitals. The meetings are only one a month or one every two or three months!” (MA)

“When I attended the support group meeting, it’s more on one-way talk instead of two-way and for me, that is still not enough”. (ZT)

What made the face-to-face support group unfavourable was the fact that it was intended only for children with ASD. So, parents felt that they too need a support group.

“Apart from the child, parents also need support. But we don’t have that in Malaysia. So, Autisme Malaysia is the avenue for parents to get support”. (MA)

Not only was the nonexistence of local online support groups the motivating factor, the scarcity of information related to ASD from the local government was another reason as expressed by the participant in the interview transcript below. Hence, the only option was to share information available in other countries with parents in the AM FB group, an example as in Figure 4.3, hoping that it could be applicable in the Malaysian setting.

“When I came back to Malaysia end of 2010, for about a year I felt lost because no one here understands me. I couldn’t get the information that I wanted here in Malaysia. When I was in Japan, everything is at your fingertips (online). I can easily find information because they (Japan) are very organised and if I need assistance or support group, I can easily go to their council as everything (information) can be found there”. (NS)





Figure 4.3. Sharing information from sources outside Malaysia

The motivation to join the AM FB support group was also driven by the challenges that these participants faced. The most cited challenge faced by the participants was education-related matter, followed by medical-related matter which included diagnosis, treatment and therapy.

“My daughter was three at that time. So, I need to know which school (kindergarten) to send her. What are the facilities that Malaysia has to offer for my child? That info is not available on the internet”. (ND)

“My son was 6 and I had a problem in getting information. By 7, he would be enrolled in school and yet I have no idea which school should I put him into, which school should I choose, what are the requirements and procedures? I am clueless who to contact, which department is responsible as this information is not easily available”. (NS)

“I don’t know where to find info here in Malaysia. I brought my son to see a doctor at the general hospital, even to private hospitals and specialist just to get him diagnosed”. (NS)

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Even when the medical-related matter was being pursued by the parents, it took a very long time to follow the procedure of the government hospital as justified by the participants in the interview transcript below to support the status posted as in Figure 4.4. All these challenges had motivated the participants to join the AM FB support group.

“When my son was two, I took him to a local government clinic and the nurse told me that he did not have a typical development for a two-year-old. So, she made a referral to the government hospital, firstly the outpatient clinic. Only later he was referred to an occupational therapist, speech therapist, ENT specialist, paediatric and finally psychiatrist.

All this process took about two years when he was formally diagnosed and we got appointments for therapies. So, he started therapies when he was four and sometimes they would be once a month or one every three months”. (AL)



Figure 4.4. Parent sharing medical-related issue.

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Despite all these motivating factors, some parents were motivated to join the group merely for seeking more information and knowledge on ASD although they did not have a child with ASD as could be seen in Figure 4.5 of Facebook data below.



Figure 4.5. Motivating factor to join the AM FB group.

### ***Motivating factors for others to join the AM FB group***

When the participants joined the AM FB support group for the first time, most of them engaged as observer or *lurkers*. They chose to read what members posted on the AM FB wall and the comments given by others. Only after some time did they feel, the urge to take action by engaging highly in the conversation on the AM FB wall. They were considered as highly engaged as they started to participate by:

- i) posting status on the AM FB wall
- ii) commenting on other members' status,
- iii) 'Like' a status/comment
- iv) 'Share' a link from a different source (websites)/ others' status

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These activities conducted on the AM FB *wall* were the computer-mediated communication that these participants engaged in. The frequency of these activities being conducted by the participants was discussed in the participant observation section earlier. The quantitative analysis indicated the frequency of the activities which was related to high/low engagement of the participants in the AM FB group. The more frequent participants posted statuses on the *wall*, the more highly-engaged they were with the group.

Most participants chose to finally post a status or comment to the AM FB *wall* when they had a doubt pertaining to their child. They felt the urge to take action by participating in the online communication for the benefit of both their child and themselves. They viewed sharing things on the *wall* as a way to communicate with other parents as could be seen in the interview transcript below.

“After some time when I feel that the information that I got from AM FB group is really useful and I can share anything with other parents, that’s when I start to join (*post to AM FB*)”. (JB)

“All parents in AM FB group are the same. When they feel down or their child has a problem at school, they will share it in AM FB”. (AL)

“I joined AM FB in 2012. At that time, I logged in every day and I updated status every day because it’s more of sharing my feelings with others”. (LW)

Sharing experiences and information on the AM FB *wall* was also perceived as a social platform to build networking and socialise with other parents who shared the same experiences as them. All this sharing became a motivating factor for others to join actively in the AM FB support group. Most participants shared challenges and positive improvements of their child on the AM FB *wall*. Figure 4.6 illustrated a status that could motivate other parents to join and communicate on the AM FB group as this parent shared

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what he had obtained by joining the group, followed by interview transcripts to justify the status.

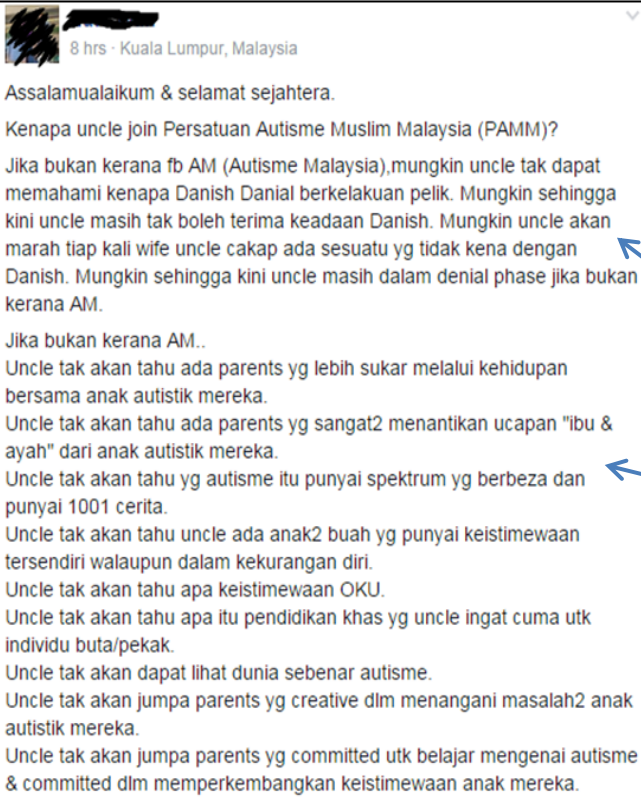
 <p>Assalamualaikum &amp; selamat sejahtera. Kenapa uncle join Persatuan Autisme Muslim Malaysia (PAMM)? Jika bukan kerana fb AM (Autisme Malaysia), mungkin uncle tak dapat memahami kenapa Danish Danial berkelakuan pelik. Mungkin sehingga kini uncle masih tak boleh terima keadaan Danish. Mungkin uncle akan marah tiap kali wife uncle cakap ada sesuatu yg tidak kena dengan Danish. Mungkin sehingga kini uncle masih dalam denial phase jika bukan kerana AM.</p> <p>Jika bukan kerana AM.. Uncle tak akan tahu ada parents yg lebih sukar melalui kehidupan bersama anak autistik mereka. Uncle tak akan tahu ada parents yg sangat2 menantikan ucapan "ibu &amp; ayah" dari anak autistik mereka. Uncle tak akan tahu yg autisme itu punyai spektrum yg berbeza dan punyai 1001 cerita. Uncle tak akan tahu uncle ada anak2 buah yg punyai keistimewaan tersendiri walaupun dalam kekurangan diri. Uncle tak akan tahu apa keistimewaan OKU. Uncle tak akan tahu apa itu pendidikan khas yg uncle ingat cuma utk individu buta/peka. Uncle tak akan dapat lihat dunia sebenar autisme. Uncle tak akan jumpa parents yg creative dlm menangani masalah2 anak autistik mereka. Uncle tak akan jumpa parents yg committed utk belajar mengenai autisme &amp; committed dlm memperkembangkan keistimewaan anak mereka.</p> <p>Itu semua mungkin terjadi jika uncle tak mengenali AM &amp; uncle sendiri tidak mempunyai anak autistik. Kerana sebab2 diataslah uncle tergerak hati untuk menjadi ahli berdaftar PAMM. Itulah keistimewaan PAMM di mata uncle. Itulah yang AM sumbangkan pada uncle selama ini. It is something priceless. Wassalam.</p> <p>Like Comment Share</p> <p>You, Nora Yusof and 69 others like this.</p>	<p>Greetings.</p> <p><i>Why do I join Autisme Muslim Malaysia (PAMM)?</i></p> <p><i>If not for AM FB, I would never understand why Danish Danial was acting weird. Maybe I still couldn't accept his condition. Maybe I will keep getting angry when my wife told me there's something wrong with our son. Maybe till now I'm still in denial if not for AM.</i></p> <p><i>If not because of AM, I will never know that other parents face greater challenges with their children compared to me. I will never know there are parents waiting for their children to call them 'mom' and 'dad'. I will never know that ASD has a broad spectrum with different disorders. I will never meet other parents who are committed to learning about autism and developing the potentials of their children.</i></p> <p><i>This is what AM contributes to me all these years.</i></p> <p><i>It is something priceless.</i></p>
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Figure 4.6. Motivating others to join and communicate actively on AM FB.

"I'm housewife so after sending my daughters to therapy, to school, I have no time for

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myself, unlike those working mothers who can meet friends for lunch. So, this (AM FB group) is the outlet for me to socialise”. (ND)

“Eighty percent of the members in AM FB group are parents who have direct experience with their children with ASD. So we can share tips and experiences. We just want others to listen to what we express, not so much of solving our problem. It’s a channel for us to share and build a network with them”. (MA)

### *Challenges faced by parents of a child with ASD in Malaysia*

One of the most cited challenges that these participants faced was financial constraints. Due to the long wait for diagnosis and therapies at the government hospitals, parents would prefer to send to the private hospitals but this incurred higher cost. However, not all families could afford to opt for private services as illustrated in the Facebook status (Figure 4.7) and this was supported by the interview transcript below.

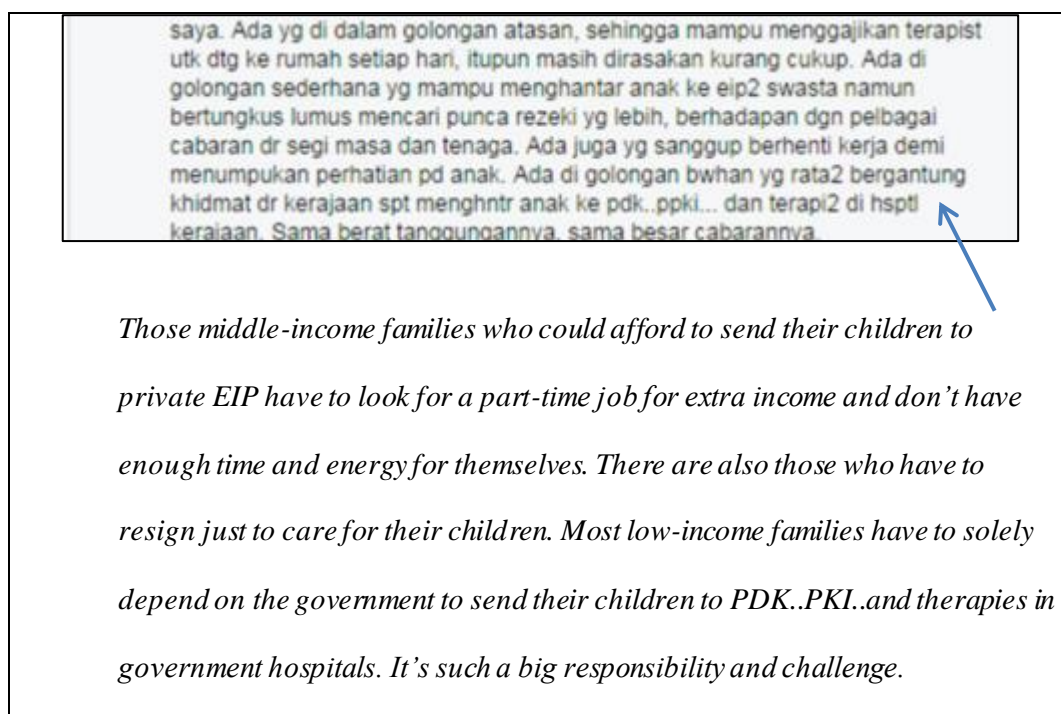


Figure 4.7. Challenges faced by parents.

“This is the best platform I would say, in Malaysia if you don't have a million bucks, this is

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the best platform (*AM FB*). If you have a lot of money, you can do ABA and all costly things.

But this (*AM FB*) is an average Malaysian way of dealing with autism”. (ND)

Thus, the *AM FB* support group became the platform for these parents to learn from one another especially the therapies that they could do at home with their child. This was the only way to substitute their inability to afford the private services.

Parenting a child with ASD was definitely a challenge for these participants especially when they had other typically developing children. Parenting issues involved different aspects of behaviour, discipline, education and outing. Behaviour was the most cited parenting issue raised both in the archived Facebook data and the interview. It was the most frequently-shared issue on the *AM FB wall*. This is because ASD was a condition closely related to the repetitive and unpredictable behaviour of the children and parents had difficulty in managing them. Things became even worse when the child with ASD had a little sister or brother as they could not understand how their action could be damaging to others. This was the peak of the challenges parents faced in parenting a child with ASD. Figure 4.8 and 4.9 below showed a Facebook status of a parent expressing anxiety over their child with ASD which denoted parenting issues.



Figure 4.8. Parenting issue on child's therapy.



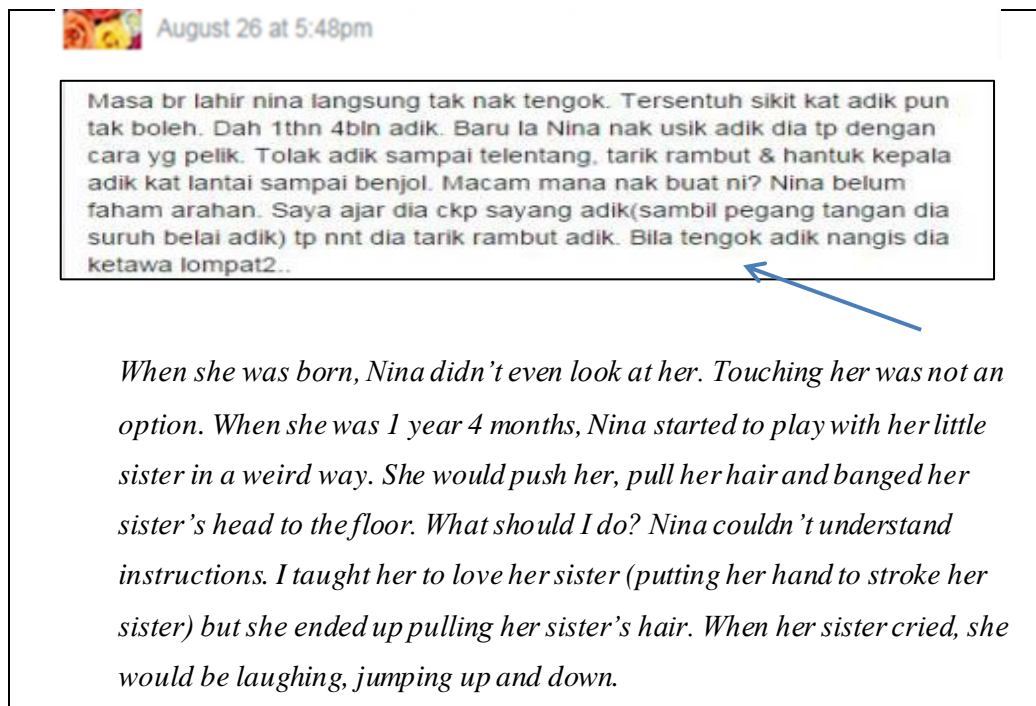


Figure 4.9. Parenting issue involving children with ASD and typically developing siblings.

Dealing with the children's behaviour was hard enough for these parents and it became more challenging when they had to deal with the education-related issue such as children's reluctance to attend school. This was illustrated in Figure 4.10. The challenge kept piling up when there was pressure from the school (administration/teachers) as shown in Figure 4.11.

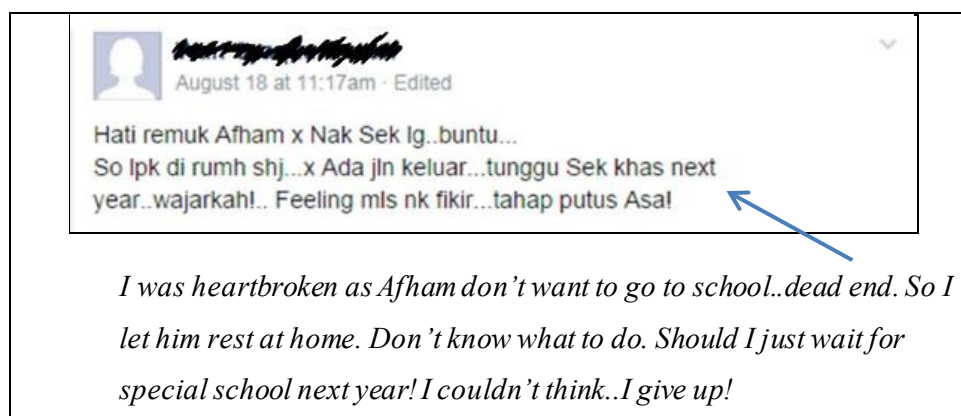


Figure 4.10. Education-related issue.



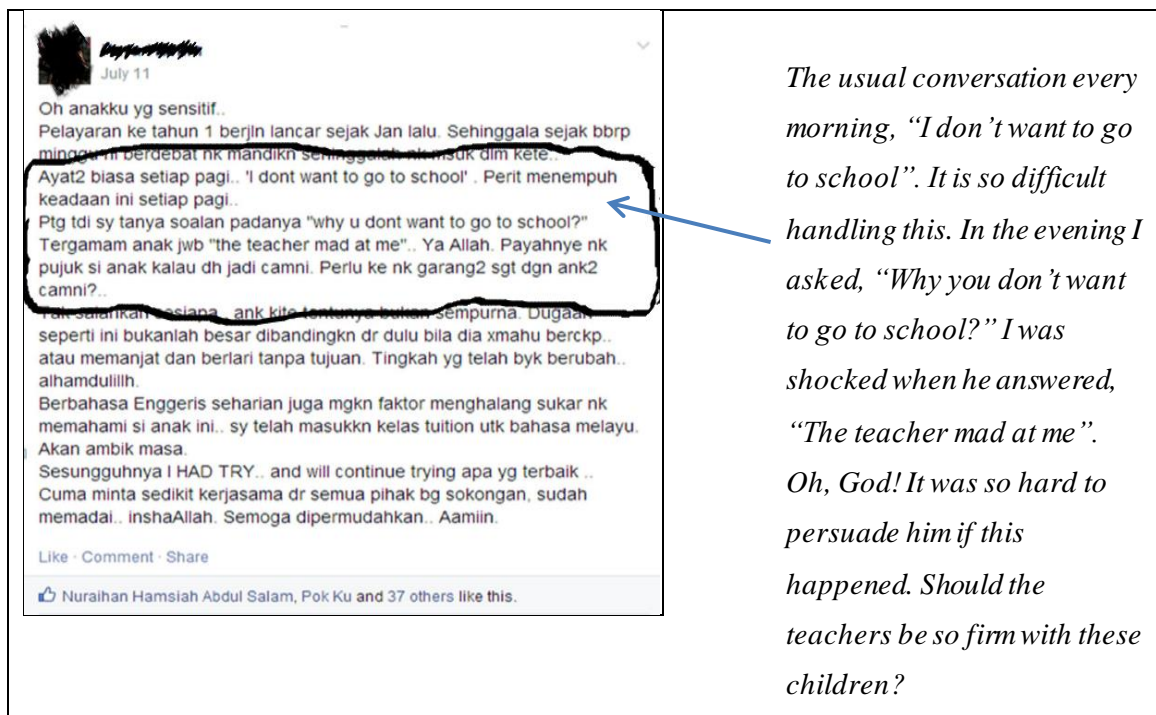


Figure 4.11. School administrator/teacher-related issue.

Data from the interview also suggested the participants' struggle with the school-related matter as illustrated below and Figure 4.12 showed parents' internal struggle due to the school rejecting the child with ASD. It was difficult for the child with ASD to adapt to the school environment and to have him removed from the school was another challenge both for the child and the parents.

"I have to find another school for him as he was rejected from the previous kindergarten".

(AL)



*I was so sad this morning getting a call informing that my child is rejected by the kindergarten that he attended previously with the reason that he is too slow in learning in class..totally speechless now I have to find a new kindergarten soon..Ifelt like crying..if only I could resign my job and home-schooled him..I don't mind how hard it is..*

Figure 4.12. Parent's internal struggle.

Parents also faced a greater challenge when taking the child to an outing, for example, to the park, shopping mall and even hospitals. Due to the non-typical behaviour shown by the child with ASD, the general public mostly gave a weird look or a gaze at the child and the family. Figure 4.13 illustrated the social stigma of the general public giving the gaze while the interview transcript highlighted the social stigma from her own family members.

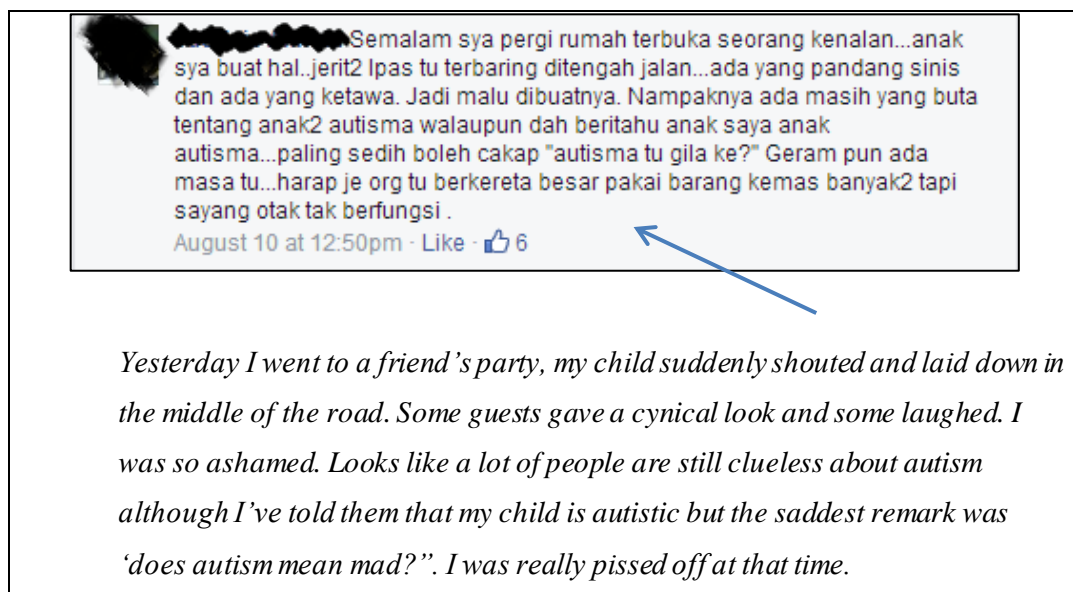


Figure 4.13. General public giving the gaze.

“Since autism is not a physical ability, so others find it hard to understand. Even my own family couldn't understand it”. (ND)

All these challenges posed an emotional stress to parents at an earlier stage but as time passed by and they became more experienced in managing parenting issues, they began to accept the child with ASD as special and ignore the stigma that the public had on them.

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

Engaging in communication on the AM FB group had assisted in accepting and adapting to these challenges. This was evident when most of these participants started to shift their purpose in posting a status/comment about their challenges to sharing more positive improvement about their child with ASD.

### ***Positive improvements of the child with ASD***

The participants mentioned that after engaging in the communication on the AM FB *wall*, there was a prominent transition that they went through. The earlier statuses they posted were more negative where they usually expressed their frustration, depression and anger. However, they realised a shift to a more positive posting after some time being in the AM FB group. This could be seen from the interview transcript below.

“In the beginning as I can recall, my postings were rather negative the negative experience at an earlier stage with school issues and other problems. It’s more of a place to dump my anger and such. But now, my postings are more positive that I would share tips etc.” (ZT)

This transition proved that the AM FB was an agent of change. It could be linked to the theme of motivating factors to others as sharing experiences on the AM FB *wall* had provided not just a sense of relief to find someone who shared the same experiences and feelings but enable them to learn from each other as could be seen in Figure 4.14. Sharing about the improvement of the child, particularly in behavioural and educational aspects, offered a boost of hope for other parents in the AM FB group that their child could turn out the same. Even a little improvement would mean the world to the parents and that was what the admins encouraged other members to share on the AM FB *wall*.

“Parents usually share their children’s reading, counting and other progress. It can be a tiny thing but we (*parents of a child with ASD*), are overjoyed! Even if the child can draw a crooked line from a straight line..that was an achievement to be celebrated!” (NS)



Figure 4.14. A sense of bonding in AM FB was extended offline.

The transition of the child from struggling to improving that parents shared on the wall was also a reflection of the parents' transition. This could or could not be realised by the parents but their statuses revealed it. Other parents even became aware and able to identify other children's improvement through the status that their parents' shared. This showed the members' high online engagement with the AM FB group. The high online engagement created a sense of bonding with the group that the participants regarded as family bonding. These could also be seen when participants were able to tag the name of other members and what they were known for.

"This is my family, new extended family who understands me. After two years we can really see how this child improves and the other child progresses, we can really see". (ND)

"Mrs KN, Mrs NS and Mr LW always share a lot of things on how to educate the children.

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For example, NS frequently shares activities she did with her son at home and KN is well-known for her social story writing and drawing with her son”. (RA)

This bonding among members encouraged them to support each other which was aligned with the intention of the setting up the AM FB support group. This support mechanism was achieved by utilising the features offered by Facebook which provided both synchronous and asynchronous communication.

### *Features of Facebook used by the participants*

Facebook provided vast linguistic and paralinguistic features which its users could utilise for different purposes. The former included posting a status on the Facebook *wall* and writing a comment on the users’ own status or other users’ status. The paralinguistic features included buttons that users could click such as ‘Like’ and ‘Share’, feelings, tagging, checked-in place, among others. As discussed earlier in this chapter, there were a lot of statuses and comments made by the participants which denoted linguistic features being used on Facebook. When analysing the paralinguistic features on Facebook, findings in this study revealed the two most utilised features on the AM FB support group *wall* which were the ‘Like’ button and feelings intensifier.

The most utilised paralinguistic feature in the AM FB *wall* by the participants was the ‘Like’ button. Most participants agreed that ‘Like’ was a way to indicate support to other members who posted a status/comment. As cited earlier, even a little improvement of the child encouraged others to hit the ‘Like’ button as a way to ‘celebrate’ the child’s achievement. This was also related to the sense of bonding that the members possessed.

“Sometimes a tiny progress that parents shared about the child is really BIG for us! I will ‘Like’ that status as a way to encourage the parents and the child. People (not a member of AM FB group) may look at it as petty but not for us”. (MA)

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The sense of bonding and offering support through 'Like' extended beyond the networking that they had. It meant that these participants would 'Like' the status being posted due to its content rather than whether they knew the parent who posted it. The participants regarded the number of 'Like' as a catalyst for emotional support. The more 'Like' that they received indicated more parents extended their support to them.

"Even if I don't know the person but the status that they posted...I know they really need the 'Like', it means the world to them. One 'Like' means one person understands you. When we see those 'Like', it is priceless to us". (NS)

"After I saw the responses to my status and people 'Like' it, I became more enthusiastic. It feels that I have friends because others (*outside of AM FB group*) would not understand.

Everyone in there gives support and I become more confident"! (AL)

In return, these participants would 'Like' others' statuses as well because they realised the effect of the 'Like' on them would offer the same effect to other parents.

"Yes, I always 'Like' others' statuses because I know they will feel exactly how I feel to get the 'Like'". (AL)

Although the 'Like' seemed to be the most powerful tool to provide emotional support for these parents, the content influenced the decision for them to 'Like' the status. Participants would easily 'Like' a status that had a positive note rather than negative. A positive status would commonly generate hundreds of 'Like' as in Figure 4.15. The positive status that parents shared included narratives on the child's improvement, teachers' and schools' support and parents' self-motivation. If parents were to post a status that seemed to be negative such as criticising and condemning teachers, schools and other parents, it would not be getting any 'Like' from these participants.

"Sometimes they (*parents*) will post irrational things, attacking others who have done a lot



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for autism society such as Permata, I will not 'Like' that status". (KL)

"I will just ignore the negative statuses". (JB)

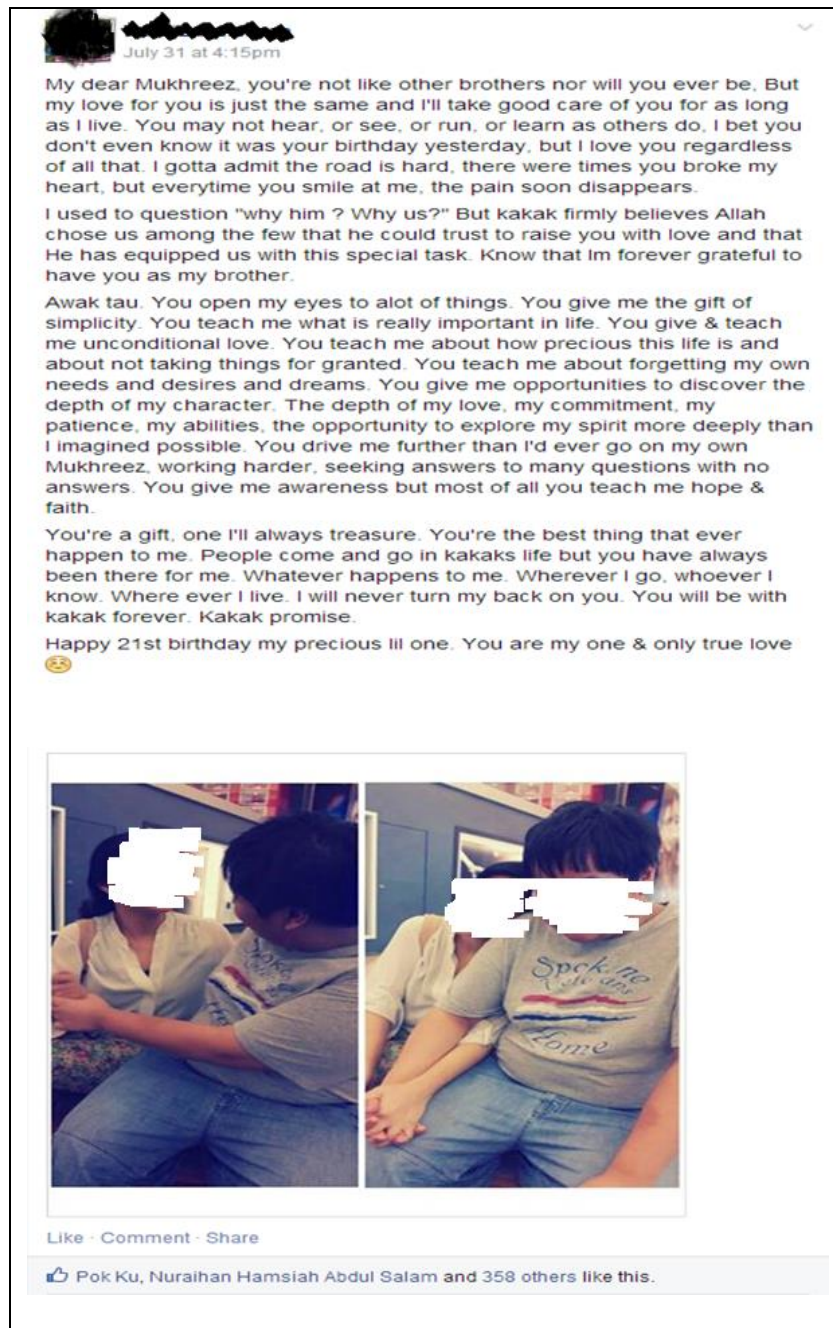


Figure 4.15. An example of positive status generating many 'Likes'

The 'Like' feature on Facebook was highly valued mostly by the new members of the AM FB group. Those who had been a member for more than three years would appreciate a comment rather than 'Like' although they used to feel motivated to get a 'Like'

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when they were new to the Facebook group too. Most participants who realised the power of 'Like' would do so especially to the new members.

"To get the 'Like' is really encouraging for me, even if they (*other members*) don't give any comment, 'Like' is enough for me!"

(JB, who had joined the AM FB group for a year)

"I always 'Like' others' statuses as I'm afraid if they don't get any 'like', they will feel demotivated to post anymore as others seem to ignore them. The new parents especially like to introduce their children with ASD and talk about them, so, I will 'Like' it".

(KL, who had joined AM FB group for 4 years)

Parents who had been a member of the AM FB group for some time, appreciated a comment even more than 'Like', even a single sentence of wishes would be sufficient as a support mechanism as shared by the participant in the interview transcript below.

"When others commented on my status, it made me overjoyed! It can be as simple as, Hooray for Uncle LW, for a status such as my son is finally diaper-free today. That gives a big impact on me".

(LW, who had joined the AM FB group for 5 years and one of the admins)

"Personally I don't look at the 'Like' but prefer them to comment, respond to what I have written. I will 'Like' others, though".

(ZT, the main admin)

Another Facebook feature utilised by most participants was the 'Feeling' that could be embedded in the status. The purpose of this feature was to accentuate the feelings that the parents tried to express in the status. Facebook provided an emoticon for every feeling, both positive and negative as could be seen in Table 4.3.



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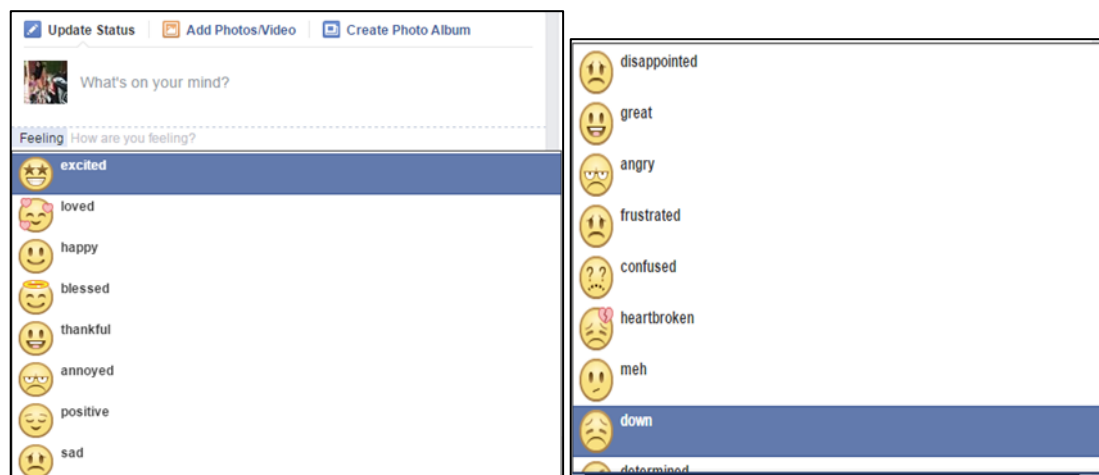


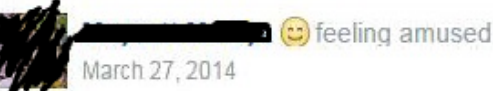





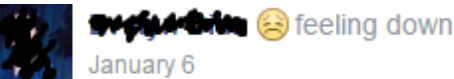

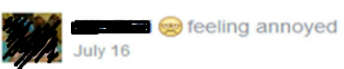


Table 4.3. Types of emoticons available on Facebook

Based on the archived Facebook data, most participants utilised emoticon for both positive and negative feelings based on the experiences they intended to share on the AM FB wall. However, the most frequently used emoticon was the positive feelings rather than the negative feelings as illustrated in Table 4.4 below. This could indicate that despite facing challenges related to the child with ASD, parents in the AM FB support group remained positive.

Table 4.4.

*Emoticons Used by Participants in AM FB Group*

Positive feelings	Negative feelings
      	   

*Language use when posting to the AM FB wall*

The symbolic communicative features of ‘Like’ and emoticons that these participants used accompanied the written language in their status. Although they had the freedom to express whatever they wanted on the AM FB wall, they felt restricted to the language use. This restriction was not imposed by the admins but driven by their own awareness of others’ feelings. The choice of words was made carefully while writing the status and most would read it few times before posting it to the wall as a way of editing the language. This was done so that the language used would not be offensive to other members. This careful planning did not only involve status with a negative note but also with a positive note, for example, a post on the child’s achievement. Statuses with a negative note such as expressing dissatisfaction over teachers’ and school’s treatment of the child and frustration over child’s

behaviour were quite obvious to have the ability to offend others. However, to have a status with a positive note that could become offensive was a shocking finding given the fact that the AM FB group was indeed a support group for parents seeking social support. The reason behind this was that the excitement over the positive improvement of the child could inflict stress on others especially if they had a child of the same age that did not improve. Thus, to minimise this, parents would regularly check their language when writing a status and edit it before posting it to the AM FB *wall*. Some even stated clearly at the beginning of their status that this posting was not meant to be boastful of their child's achievement. Others would state their intention of posting at the end of their narrative as illustrated in Figure 4.16 below where the gentle reminder was written as 'footnote'. This was the way to maintain a harmonious vibe in the group. The interview transcripts below illustrate how participants' were vigilant when writing a status or comment and justified the strategies taken to not offend other parents as explained earlier.

"I tried very hard not to get too excited when writing and always be careful with my language as my main intention is to give hope to others". (NS)

"We always have to be polite when posting or commenting. We can't be harsh". (RA)

Despite this careful choice of language when writing a status or comment, it did not prevent participants from writing longer narratives. As the number of words was endless when posting to a Facebook wall, participants could 'pour their hearts out'. Later, others provided support through understanding and extending the response in a compassionate network of members (Yager, 2001) in the AM FB support group.



Figure 4.16. An example of using politeness in giving gentle reminders on the intention of the post.

## *Asynchronous and synchronous communication in the AM FB group*

This sensitivity to the language used was to not offend other parents and it was practised by the participants both for asynchronous and synchronous online communication. Asynchronous referred to the communication that took place on the AM FB *wall* while the latter referred to communication in the form of chats that involved two members or a group where a few members could chat at the same time. This feature on Facebook allowed the members to decide which type of communication suited them best. Chats, better known as a private message (*pm*) between Facebook users was the type of communication that members opted for when they needed to further clarify with the member posting the status especially for those who felt shy asking publicly on the AM FB *wall*. Facebook allowed the members

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to *pm* other members in the group without having them to become 'Friends'. This encouraged members to network with those people they felt could be the source of information and support for them to manage their child with ASD.

Although synchronous communication was thought to advantageous, a shocking finding in terms of what pms were used was that some utilised it to criticise what the participant had posted on the *wall*. Instead of criticising openly on the *wall*, they chose to use the *pm*. This would not reveal their identity to the rest of the members of the group unless the person receiving the criticism upload it on the *wall*. This finding was shocking as the researcher did not expect this kind of response in a support group, especially a support group for parents of a child with a disability. To make things worse, some parents even sent a private message asking the participant to reduce the frequency of their statuses posted on the *wall* as this could make others have high hopes for their child as shown in the interview transcripts below.

"Whenever I posted on the wall, some parents were not satisfied. They would pm me and said that I was trying to show-off my son's ability. No! That's not my intention. I would feel hurt to get such comment".

"I used to get a pm (private message) saying, could you please not post too much status as other parents may have high expectation of their children, so why don't you put it on your blog". (KL)

Despite misuse of the private message function by some parents, both asynchronous and synchronous communication helped motivate parents to become more open about their children. Six of the twelve participants claimed that they found the courage to post a status/comment on the AM FB *wall* after engaging in synchronous communication with other experienced parents through private messages and when they felt the need for more support from other members.

“I prefer a more personal communication (*private message*) rather than posting on the wall, but when I feel empty and want more comments, then I will post on the wall”. (RA)

#### 4.2.2 Expression of feelings

As described earlier, the AM FB support group was used as a communication platform to share things mostly related to their child. Apart from discussing matters related to their child, parents utilised online communication for their own benefit, which was to get support. They engaged in communication that revolved around expressing their feelings. These feelings were closely related to their child with ASD and the challenges that they faced. The expression of feelings was usually embedded in the narratives that they shared on the AM FB *wall*. The feelings were divided into negative and positive, shown in Table 4.5.

Table 4.5.

#### *Feelings Expressed by Participants on AM FB wall*

Negative feelings	Number of references coded	Positive feelings	Number of references coded
• Anxiety	16	• Hope/wishes	46
• Hatred/anger	5	• Joke	6
• Disappointment	21	• Love/like	4
• Loneliness	3	• Astonishment	12
• Regret	13	• Excitement/happiness	36
• Sadness	14	• Gratitude	89
• Shock	7		
• Give up	3		
• Lost	2		

#### *Negative feelings*

All the twelve participants stated that at the beginning of their active participation in the AM FB, they used to post statuses expressing negative feelings. Apart from the frustration of their child’s behaviour and attitude, most of these negative feelings were

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related to dissatisfaction and pressure the parents felt dealing with other parties such as school administration, teachers, doctors, employers, and society in general. This caused emotional stress for the parents and it became worse when those other parties would still not understand even after being told that their child had ASD. Among the negative feelings listed above, disappointment was the most frequent. Figure 4.17 and Figure 4.18 illustrated such disappointment.

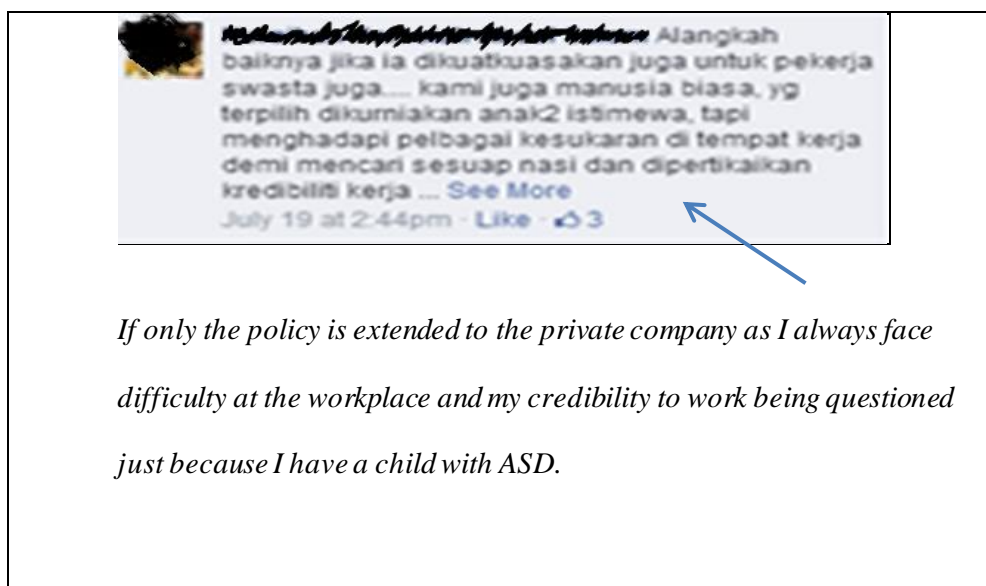


Figure 4.17. Feelings of disappointment expressed on workplace's policy.

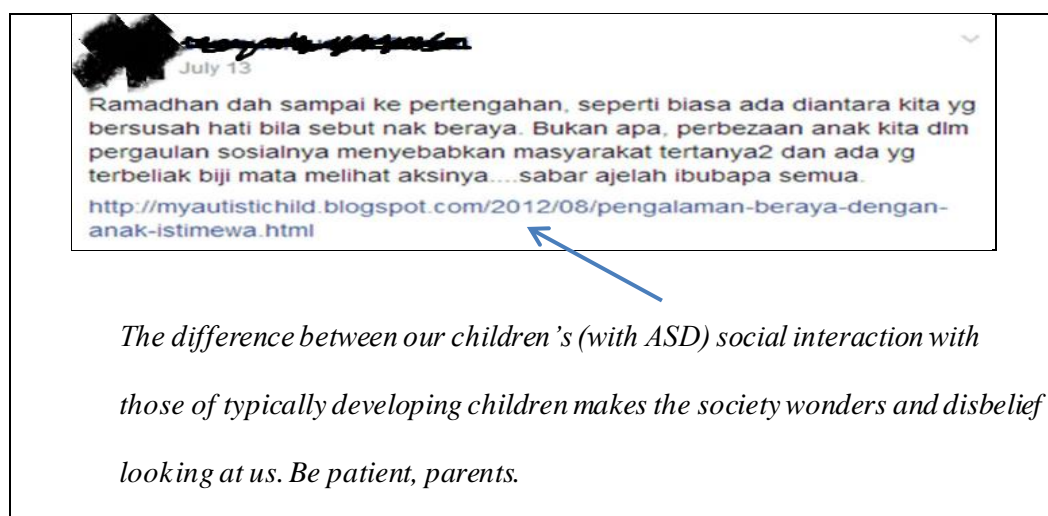


Figure 4.18. Feelings of disappointment expressed over public's gaze.

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

The second highest negative feeling expressed on the AM FB *wall* was anxiety.

Anxiety was mostly expressed by these participants wondering their child would cope with their surroundings, especially at school. This included their behaviour and action in the classroom towards the teacher and their social interaction with peers. This was due to the fact that children with ASD have difficulty with speech and social communication. As mentioned earlier, most of these expressions of feelings were written in an anecdote style. Figure 4.19 below includes a narrative of the conversation between a mother and her son with ASD in which the son expressed his sadness of finding it difficult to make friends, both of the same gender and opposite gender. This later made the mother felt anxious on how the son could cope with this and her disappointment of other people's inability to understand ASD. On the surface, this anecdote seemed to be just a sharing of feelings, but reading between the lines, it indicated the participant was seeking emotional support from other members. This status garnered 50 'Likes' and 28 comments in which all the comments offered emotional support to the mother.





Figure 4.19. Narrative used to express feelings of anxiety.

Expressing sadness was the third most frequent feeling shared by these parents. It was expected that parents would feel sad, especially when they were unable to manage their child's behaviour and attitude. This led to emotional stress and the challenge of coping with it. Thus, the only way to alleviate such stress was to share it on the AM FB wall. Another interesting finding was that an expression of sadness shared by the participants was often due to their frustration caused by the treatment that these parents received from others such as their immediate family (grandparents and relatives of the child), employers, friends, school principals and teachers, government organisations, and society in general. The intensity of sadness was amplified when the immediate family members would not understand the predicament of managing a child with ASD. Based on the interviews, there

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was even a case in which the child's uncle beat him just because he refused to return the uncle's mobile phone as he was playing a game. It made matter even worse when the child's grandparents took the uncle's side. This is the kind of situation where the parents could not contain their sadness over these actions and the only solution was to share their feelings on the AM FB wall. The feelings of sadness expressed by the participants can be seen in Figure 4.20 and the interview transcript below reinforce the Facebook status.

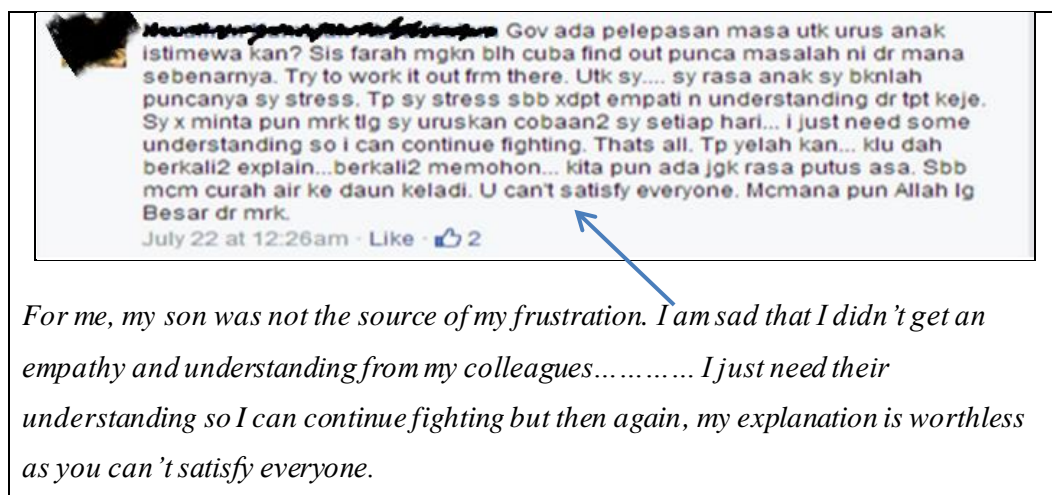


Figure 4.20. Expression of sadness over colleagues' lack of awareness.

“When we have that kind of child, we become motivated to find other parents who share the same experience as ours as they are the one who understands. Other people won't understand, not even our own parents. That made us even sadder. Their usual respond would be, it's normal for kids to start speaking a bit late. No need to register for disability card.

They were angry!” (KL)

This expression of negative feelings was another type of communication these parents engaged in the AM FB group. The difference of expressing it on that wall compared to their own FB wall was that the sense of belonging and the group dynamics in the AM FB group allowed these parents to obtain great support and understanding from the members. Expressing their feelings on their own FB walls meant they were dealing with a group of friends typically comprised of colleagues and former classmates who were not be able to

comprehend the situations and they would have lots of questions on why such things happened. Thus, these parents preferred to share their negative feelings on the AM FB wall.

## Positive feelings

As the participants become more experienced with their child, their expression of feelings on the AM FB wall shifted to more positive feelings. This shift did not only indicate the emotional state of these parents but it reflected their ability to better manage their child. This shift was influenced by the high engagement, active participation and the support that they obtained in the AM FB group. This shift was contagious to other new parents who just joined the AM FB group. Expressing gratitude was the most common positive feeling evident both on the wall and in the interviews. Gratitude was expressed both to God and to the people around them. It was mostly associated with positive improvements for their child or how they managed to get through a difficult situation using the support of AM FB group members. Being thankful for others was included in expressing gratitude as it represented similar feelings. This is illustrated in Figure 4.21 and 4.22 and the interview transcript below verified those Facebook postings.

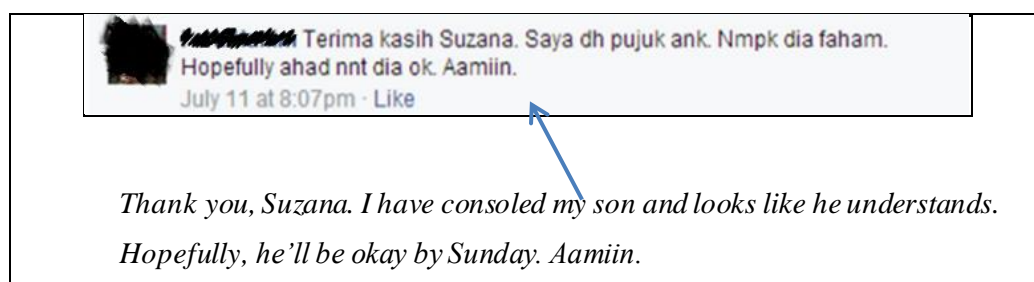


Figure 4.21. Tagging another parent's name as a show of thanks.



Figure 4.22. Expressing gratitude by tagging the name who helped improving the child's learning.

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“But this is the average Malaysian way of dealing with autism and I’m sure I cannot get this tips and the love, the love without being in AM. I’m really thankful for all”. (ND)

Expressing hope and wishes were the second most common feelings expressed by the participants. Hope included the desires that these parents had for their children would experience positive improvements, be independent, be able to speak and interact with others, and to be accepted by others. They did not have high hopes that their child would be ‘cured’ but they hoped that at the very least they would see short-term improvements. The wishes that they expressed were comprised the confidence that parents had for other children with ASD, birthday wishes, and good luck wishes for activities or therapies taken up by the children. Parents also expressed their hope and wish for themselves, teachers, society and the group specifically. Figure 4.23 and Figure 4.24 and the interview transcript below illustrated the feelings a Facebook statuses.

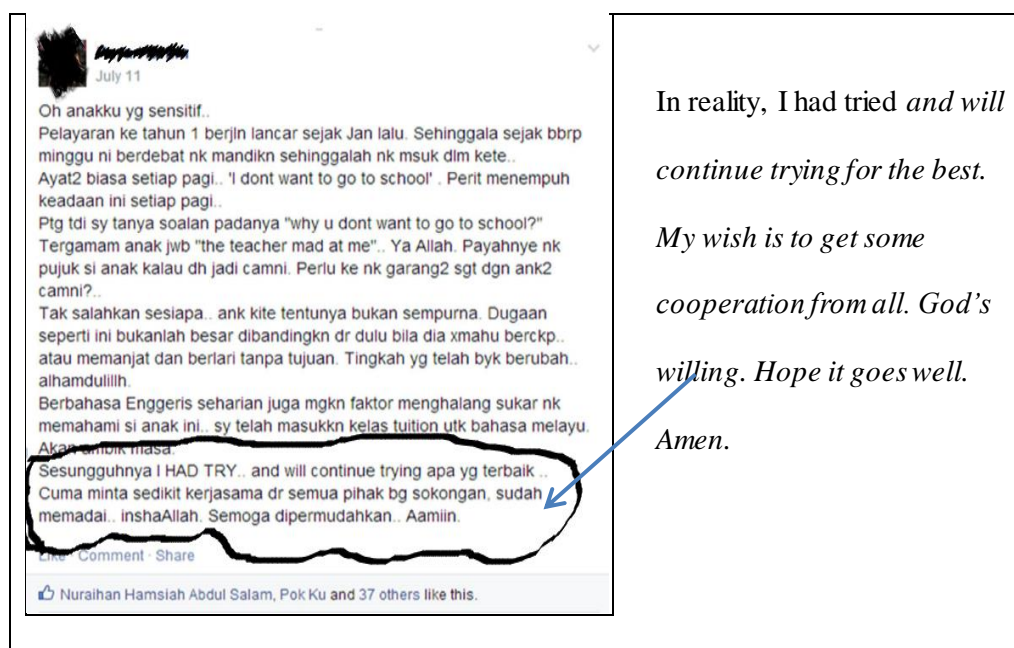


Figure 4.23. Expressing hope over child's improvement



*My hope is for us to help explain the difference between children with disabilities and children of typical development to those mainstream teachers who are still lack of awareness*

Figure 4.24. Expressing hope over teachers' understanding and awareness of ASD.

"I hope this group can help me and my son. If he lives longer, I will share his life story and experiences here (*AM FB group*)". (AL)

The third most common feelings expressed were happiness and excitement. As mentioned earlier, when parents had been members of the group for some time, there was a shift of the feelings being expressed on the AM FB wall. Most situations that had contributed to emotional stress at the beginning of their engagement with the group were now being replaced with happy and exciting situations. This was generally due to the improvements made by their child, which may have been small, but affected the parents greatly. Excitement and happiness were also expressed for the positive vibe and support these parents obtained through their engagement with the group. One example of the excitement shared on the wall was the society's initiative in creating awareness of people with disabilities as illustrated in Figure 4.25 and the virtual meeting of parents of similar experience as shown in the interview transcript below.



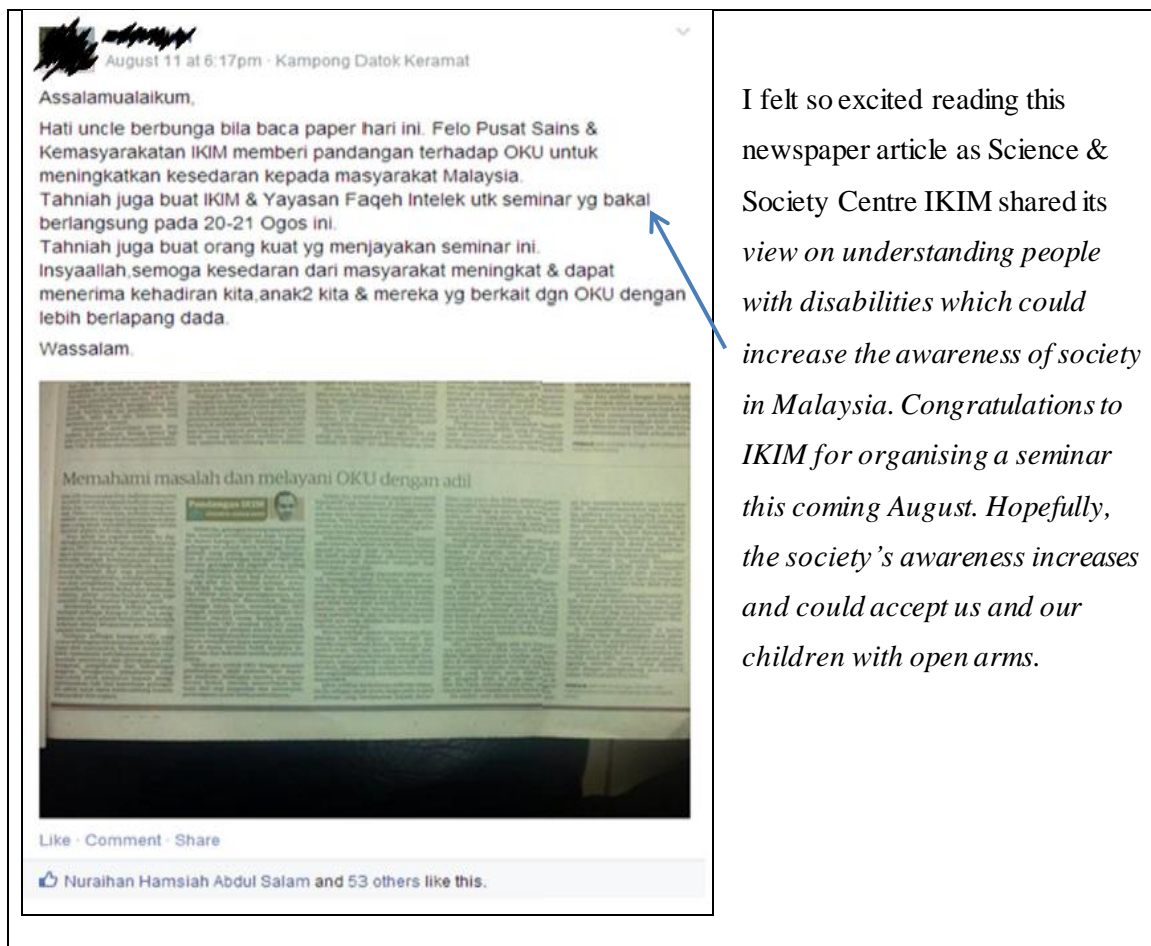


Figure 4.25. Expressing excitement over society's involvement in raising awareness on ASD.

“They (*members in AM FB group*) are very friendly and although we don't get to meet them, knowing them (*virtually*) really makes me happy! I don't have much experience (when dealing with a child with ASD) and only know the basics, but they are very experienced and know a lot more”. (JB)

### 4.2.3 Social support

The third type of communication these participants engaged in was social support communication. It involved seeking and obtaining support and giving support. All the twelve participants claimed that during their earlier engagement with the AM FB group, they tended to be focused on seeking and obtaining support. After some time, almost a year, they started to give support to others who were new to the group. Initial data analysis indicated that the participants logged into and posted to the AM FB *wall* for various

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

purposes. The majority of the statuses contained more than one theme related to social support. Table 4.6 shows the number of status related to ten themes of social support.

Sharing personal experience was the most common theme followed by informational and emotional supports. It is important to highlight, however, that most of the sharing of experiences was accompanied by other social support themes. Tangible support and affectionate support were the least shared themes.

Table 4.6.

### *Number of Postings Themes*

Themes on social support	Number of statuses (N=)
Personal experience	96
Informational	88
Emotional	72
Thanks	48
Encouragement	40
Quotes/Sayings	32
Prayer	24
Social Strain	16
Tangible	8
Affectionate	8

*Note: The total number of postings does not equal the sum of numbers in individual themes as some postings belong to more than one theme.*

On the AM Facebook wall, the sharing of personal experiences was the most common type of posting for parents of a child with ASD and there were frequently written in a form of a narrative describing what their child did. Most of these postings described their child's achievements completing a task and the post was accompanied by other themes of social support, such as expressing prayers and positive emotions (satisfaction). These ten themes were further categorised into more specific themes that illustrated similar sub-themes,

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

for example, the theme of encouragement was under emotional support. A summary of the most common forms of social support in the group is shown in Table 4.7 below.

Table 4.7.

### *Types of Social Supports Being Exchanged on AM FB wall*

Types of Support	Number of references coded on AM FB wall & Interview
• Informational support	63
• Emotional support	50
• Religious support	18

### ***Informational support***

Informational support was the most common support exchanged on the AM FB wall.

The types of information these parents sought included educational (how to register their child for school, which school to choose), therapies (types of therapies, where to find therapy centres, government or private centres, the fees for therapies session), medical-related matter (how to get their child diagnosed, who to contact, where to go, what age is appropriate) and parenting skills (managing challenging behaviours and attitudes, home therapy, time and financial planning). Table 4.8 illustrates the types of information exchanged on the AM FB wall.

Table 4.8.

### *Types of Informational Support Being Exchanged*

Types of information being sought & obtained	Number of references coded in AM FB wall & Interview
• Education	IIII IIII II
• Therapies	IIII IIII IIII



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<ul style="list-style-type: none"> <li>• Medical-related matter (diagnosis, vaccination)</li> </ul>	IIII
<ul style="list-style-type: none"> <li>• Parenting skills (how to handle meltdowns &amp; tantrums, potty training)</li> </ul>	IIII IIII II
<ul style="list-style-type: none"> <li>• Miscellaneous (radio &amp; TV shows, articles)</li> </ul>	IIII III
<ul style="list-style-type: none"> <li>• General information (what autism is, signs, supporting family, diet)</li> </ul>	IIII IIII

Most of informational support seeking was posted by the members in a form of a question. Some narrated the conditions of their child before asking for information. The information sought came in the form of facts, advice and tips. The answers were given in the form of a statement and at times followed by relevant links that contained detailed information. The names of experts were tagged so that more information could be obtained by contacting the expert. Ten out of the twelve participants offered informational support by sharing their own experience doing activities with their own child, at home or at a therapy session. Some of these home therapies were guided by therapists and some were developed by the participants' through additional reading offline and online. There were also parent who shared their experiences as they had gone through certain phases (tantrum, sensory overload, and others). Figure 4.26 shows an example of the participant seeking and obtaining informational support regarding therapies.

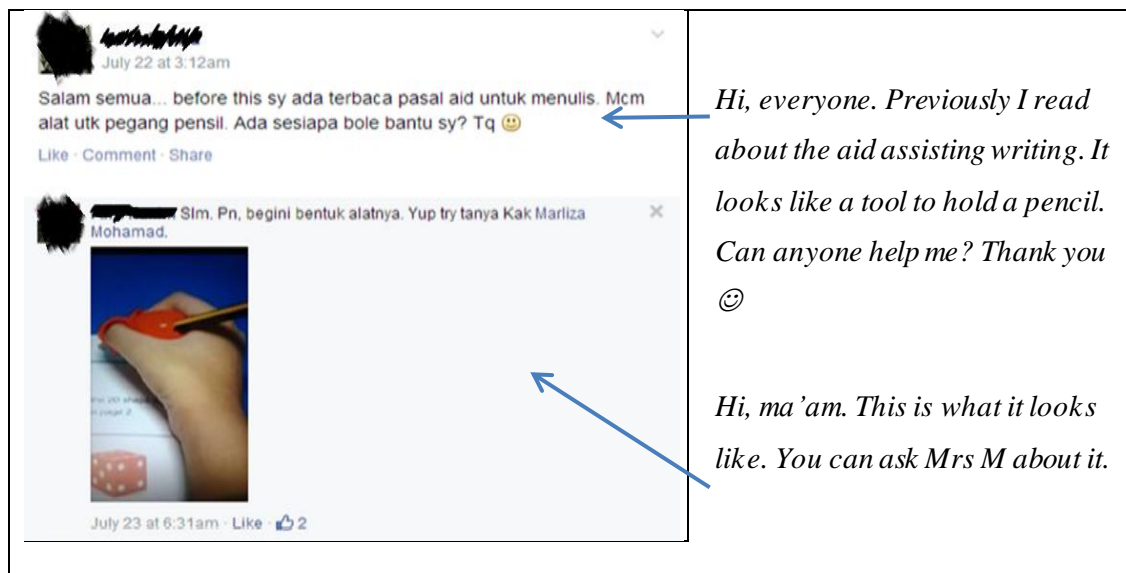


Figure 4.26. Seeking and obtaining information on therapies.

Those parents seeking informational support usually used similar approaches by using the same language structure. Their status started off with a greeting, followed by stating the problem, the information sought, and ended with a thank you as illustrated in Figure 1.17 below. This could indicate that the parents were polite when interacting in the AM FB group. It could also be an indication that others should respond kindly to such requests as polite requests would usually receive a polite response. This can be seen in the interview transcripts used to explain the status in Figure 4.27.



Figure 4.27. Seeking and obtaining information on education.

"I remembered last year when some parents asked about where to find a kindergarten that

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

would accept children with autism, so I quickly post some tips on how to find one. I don't want others to wait such a long time like I did just to get the info". (ND)

The findings of this study also showed that information on parenting skill received an equal number of occurrences as the information on education from the participants. This could indicate that both types of information were considered pivotal to these parents in ensuring that they obtained appropriate and correct informational support that would benefits of their child with ASD. Most of the parenting skills sought by the parents through their status on the AM FB *wall* revolved around how to manage the behaviour of their child. Since children with ASD are prone to behavioural issues, particularly those on the severe end of the spectrum, parents often face challenges. Having to deal with their relationship with their child with ASD and their ASD child's relationship with their typically developing siblings, drove these parents to seek informational support regarding parenting skills. Figure 4.28 below shows parent seeking informational support by narrating what the child did at home. Figure 4.28 is followed by the interview transcript substantiating the Facebook status.


 <p>July 2</p> <p>Salam. Lama dah tak post disini, sebab masih lg unclear sama ada anak saya autistic atau tidak..selepas pergi speech therapy for 10 sessions the therapist kata only speech delay and some sensory issues. Anyway, maybe some parent can advice me about 3 problem that I have with Hany (3 years old), which we don't really know how to cope.</p> <p>1) Tantrum yg melampau, kdg2 sebab tak bg apa die nak, sometime for no abvious reason. We are worried sbb bila die tantrum die hantuk kepala kat lantai.</p> <p>2) Takut air esp kalau basuh kepala.. mmg akan menjerit mcm kene air panas</p> <p>3) makan..sgtlaa pemilih.. tak suka ayam, ikan or daging.. hanya telur and nasi kosong. she like more cruncy food like keropok (which she is allergic), biscuits, and cereal tanpa susu..</p> <p>Selaga nasihat and tips sangatlai dihargai.. terima kasih. 😊</p> <p>Sensory integration activities sgt bagus. boleh pergi ot utk buat SI. dgn intensif, sama ada dgn ot atau buat sendiri di rumah dgn guidance ot, semua atas tu akan kurang. Anak saya lepas 2 bulan intensif terapi dah minta pakai tudung. Banyakkan juga aktiviti di taman utk kurangkan anxiety/tantrum. Kalau lebih 2 hari tak pergi exercise, saya apply essential oils.</p> <p>July 2 at 12:07pm · Like 1</p>	<p>Greetings. I haven't posted here for some time as I'm still unclear if my daughter is autistic. After ten sessions of speech therapy, the therapist said that daughter only has a speech delay and some sensory issues. Anyway, perhaps some parents can advise me on three problems that I have with my daughter (3 years old) which we don't know how to cope.</p> <p>Sensory integration (SI) activities are very useful and you can do it intensively during OT (occupational therapy) or at home. All your problems can be</p>
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Figure 4.28. Seeking and obtaining information on parenting skills.

“Info on diagnosis, therapies, education, and parenting are all very useful to me. They are really helpful especially for us in the north where we don’t have many centres dealing with autism. So, for me, the sharing in the AM FB group is really helpful”. (AL)

However, it was worth highlighting that at times these parents simply shared information that they believed would be helpful to others even though no such informational support was being sought by the members of the group. This information could be something that they found in other Facebook support group, websites dedicated to their child with ASD or even home therapies that were purely developed by the parents themselves. These efforts were lauded by other members in the group and some who had tried the method before would comment that it was indeed useful as illustrated in Figure 4.29 below.

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Figure 4.29. Sharing information from other FB group.

As stated earlier in the online engagement section, the lack of information from the responsible organisations and government agencies forced these parents to seek information from this Facebook support group. Thus, this explained why informational support was the most common form of social support exchanged between parents in the AM FB support group. The informational support being given and shared by the participants showed that they had experiences as they had tried and tested many of the methods with their own child and therefore implicated the confidence level and high self-esteem of these parents. It also indicated the level of trust members had in the information being shared by these experienced parents. This could indicate the positive impacts these parents obtained through high online engagement with the AM FB group.

*Emotional support*

Findings of this study suggested that emotional support was the second most common form of social support sought and obtained by the participants. Unlike informational support where parents sometimes shared information without being asked, emotional support was given only when it was asked for. This was evident when parents posted a status pouring their heart out on the AM FB *wall* expressing emotional stress. This emotional stress was closely related to the expression of feelings, particularly negative feelings. There were a lot of factors that triggered the parent's emotional stress such as the child's conditions (tantrums, meltdowns, relationship with siblings), medical-related challenges (doctor's incompetency), education-related matters (teacher's lack of cooperation), financial constraint and social stigma (society's negative impression) as shown in Table 4.9 below.

Table 4.9.

*Triggering Factors of Emotional Stress*

Triggering factors of emotional stress	Number of references
Child's conditions	IIII IIII IIII III
Medical-related challenges	II
Education-related matters	IIII III
Financial constraint	III
Social stigma	IIII IIII I

The child's condition was the main contributing factor for these parents' emotional stress. Emotional stress was made worse by their surroundings/environment, such as the parents' physical tiredness after work, a spouse who didn't help out at home, and the responsibility of taking care of other typically developing children. Due to tantrums, some children with ASD react by biting, injuring themselves, kicking the parents or screaming

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

loudly as narrated by the participant in Figure 4.30 below. As a result, these parents became more stressful and some resorted to punishing their child physically. However, the parents later reflected on their reactions and felt guilty for beating their child. They realised that their actions were uncalled for especially for a child with ASD who could not understand the repercussion of throwing a tantrum. The parents mostly realised this fact and no longer resorted to physical punishment as shown in Figure 4.31 below and explained by the following interview transcript.

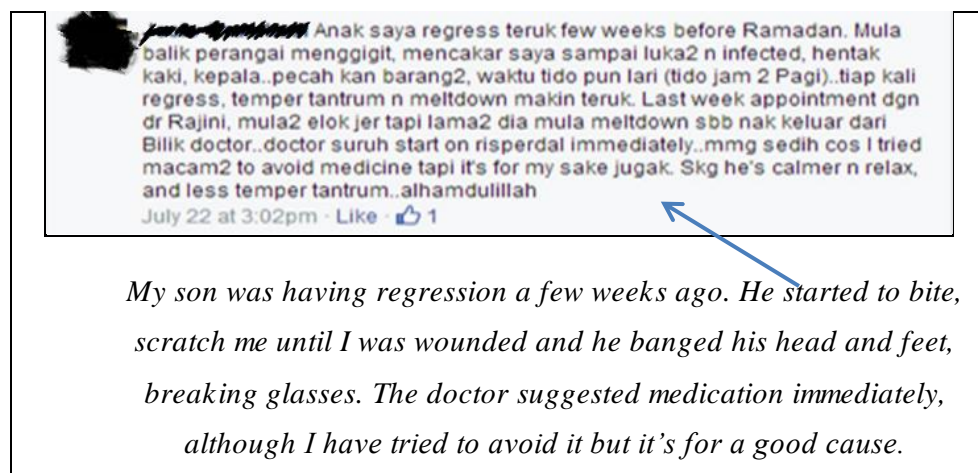


Figure 4.30. Narrative on child's severe condition.

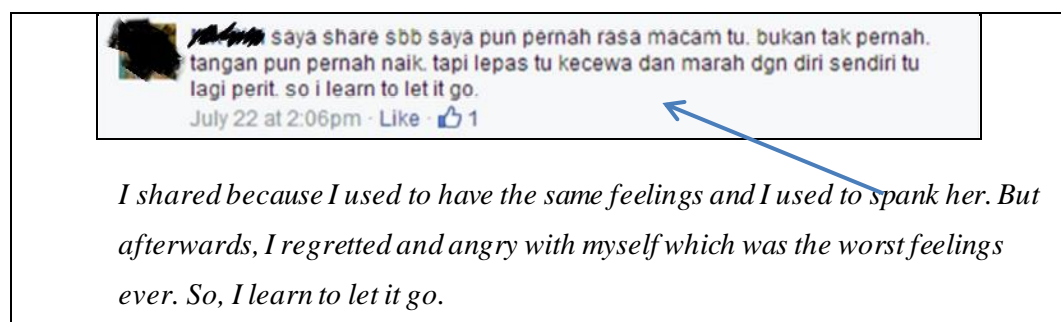


Figure 4.31. Expressing guilt over physical punishment on child.

“This is burnt out (*stress of managing child with ASD*) and parents should prepare themselves as it will be recurring. It's not the child who disappoints us, it's more of our surroundings. When we were stressful, we posted to AM FB wall and we get some sort of emotional support”. (NS)



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As the above quote from the interview data suggests, the surrounding was a contributing factor to the emotional stress of these parents. The surrounding referred to the social stigma that people around have towards children with ASD and their families. Social stigma was the second most common challenge cited by these parents on the AM FB wall. Society had a stigma that children with disabilities are easily recognised from their physical appearance such as those with Down syndrome. This stigma limits society's ability to understand that ASD is actually a disability that is not based on the physical appearance. A negative look or gaze given by members of the public is not limited to public places such as playground and shopping mall, as it can happen in hospitals and at parties. Apart from a cynical look, some people went to the extreme of making negative remarks about the child directly to the parents. Despite explaining what ASD is, they simply labelled the child as mentally retarded. Some even suggested that the child should be kept at home and not be brought to public places as he/she could disturb others as illustrated in Figure 4.32 below. This kind of social stigma added to the emotional stress that these parents had to endure and the only platform that the participants could express this was by sharing it on the AM FB wall as highlighted in the interview transcript validating the Facebook status in Figure 4.32.

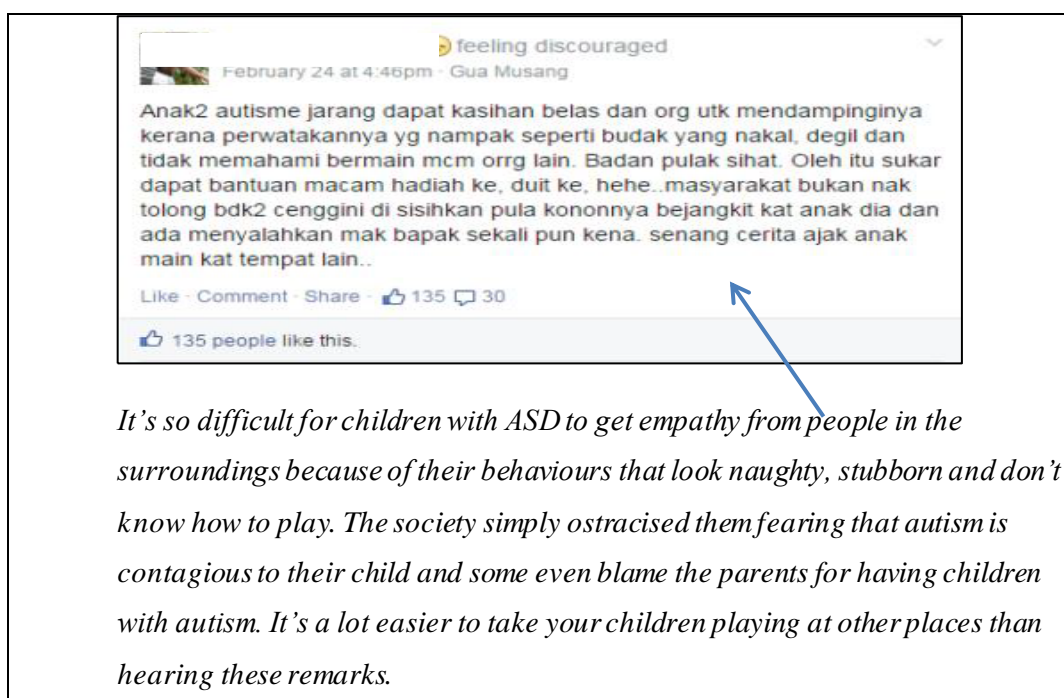




Figure 4.32. Narrating social stigma surrounding the public on ASD.

“At times, we simply want to share our feelings, not for others to solve our problem. It’s  
(AM FB wall) more of a channel for us to share, share what we feel with those who are in the  
same shoes as us”. (MA)

The negative stigma did not only apply to the general public but also to children at the school attended by children with ASD. This was glaringly evident if the child went to a mainstream school where he/she was in a class with typically developing children as shown in Figure 4.33. The capacity of typically developing children to understand what a disability is might be limited, especially if their parents had similar impressions of disability. This matter becomes worse when social stigmas regarding disabilities is instilled in their children. In addition, parents of a child with ASD faced social stigma from their immediate family members. Some of the grandparents and relatives (uncle and aunties) held a negative impression of their child. They never tried to understand that the child was special and even blamed the parents for having such child. Some easily dismissed the idea that the child was special and thought that the child was naughty and disobedient. They even claimed that the child had the disorder due to the sinful acts committed by the parents in their past lives. This social stigma from immediate family members hurt the parents even more as they expected more social support and understanding from them as highlighted in the interview transcript below.

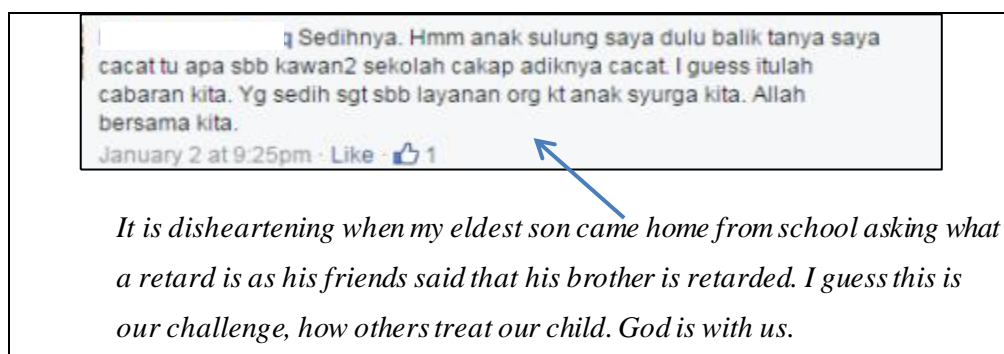


Figure 4.33. Social stigma from peers at school.

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“I used to post my disappointment of my husband’s brother who slapped my son four times just because they were fighting over the mobile phone. He even said my son was retarded! So, when I shared that on the wall, a lot of parents shared the same experience and suggested that I should avoid that person and not let my son go near him. So, I am not alone”. (AH)

Parents also sought emotional support when it came to education-related matters by posting their problems on the *wall*. As discussed earlier, some schools rejected children with ASD due to the difficulties related to managing these children and shortage of manpower. Additionally, bureaucratic administration and incompetent teachers’ dealing with children with ASD also contributed to the parents’ emotional stress. The former referred to the authoritative role of the school principal in deciding if a child was allowed to attend his school although the education policy in Malaysia clearly states that all children with a disability had the right to enrol in any school within the vicinity of their residence. However, some principals chose to violate this policy by asking the parents to transfer their child to a different school. On the other hand, principals who chose to accept these children, faced the challenge of incompetent teachers. Teachers who had undergone training as special education teachers were not trained in managing and conducting an intervention for children with ASD as shown in Figure 4.34 below. This, in turn, caused emotional stress to parents as teachers were their best hope for educating their children.


 <p>July 9</p> <p>Last Saturday had few hours session with the PDK teachers on the mana2of autism and lerning disable. Now only I found out that they are even trained in the management, even the special education teachers. Met a few trainees who came visiting, they too didn't know much. Something should be done to address this issues in equipping them on ABA and behavioral management of these childrens. A real pity since parents send their children there, PDK or special schools but they really are not really equipped with the necessary knowledge on how to do intervention. Without proper knowledge how could the children be better? Welfare department should do something soon to address these issues.</p> <p>Like · Comment · Share</p> <p>👍 Nuraihan Hamsiah Abdul Salam and 44 others like this.</p>	<p><i>PDK- Community Based Rehabilitation System (CBR)</i></p> <p><i>ABA- Applied Behaviour Analysis</i></p>
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Figure 4.34. Teachers' lack of training to teach children with ASD.

i) How was emotional support given?

There was a clear difference between how informational and emotional support were given to these parents. As discussed earlier, informational support was offered by giving facts based on reading, sharing experiences attending therapy sessions and experience based on trial-and-error, or tagging members who were experts in certain areas. Emotional support, on the other hand, was presented by giving advice and tips on how to control emotions, sharing past experiences of having the same feelings, and offering help especially on how to manage a child. This was because the most common reason for seeking emotional support was caused by the condition of the child. Most parents who gave emotional support had gone through the same phase of emotional support and they shared their experience so that others would benefit from it. Some would write in great length explaining their own child's condition, how they managed their child and how their managing skillz assisted in controlling their emotional stress as illustrated in Figure 4.35.

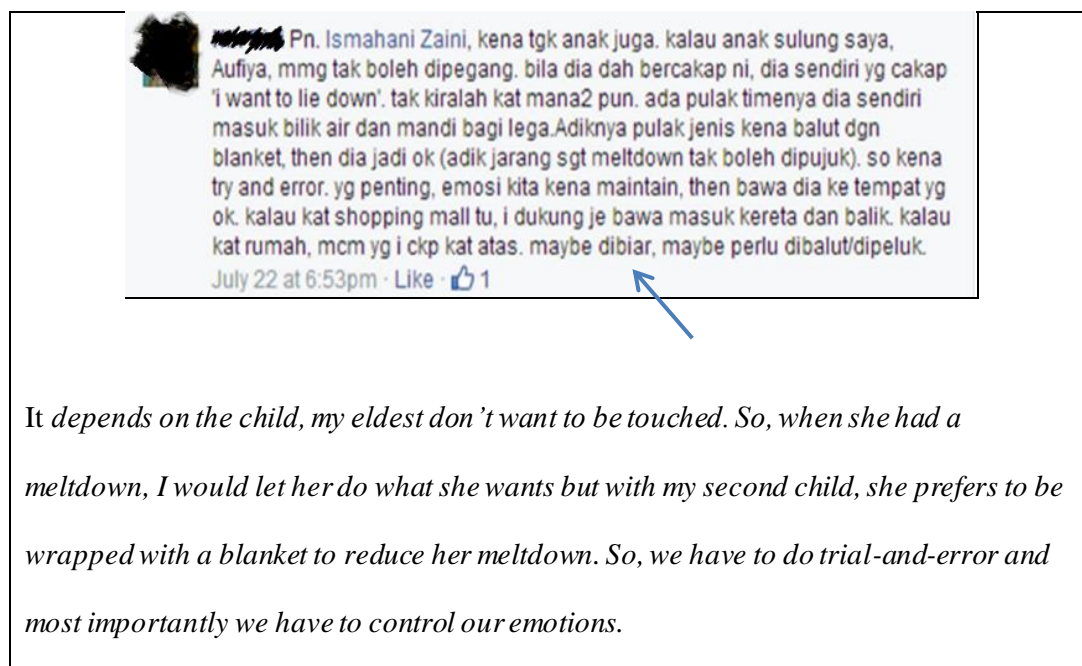


Figure 4.35. Narrating experience with child as a way of extending emotional support.

***Religious support***

Another type of social support communication the participants asked for in the AM FB group was religious support. This was closely related to emotional support as most parents were offered religious support when they shared theirf emotional stress on the *wall*. Although religious support could be another way how parents offered emotional support, it was put under a different category as this is a distinctive feature of the culture of this Facebook support group. As more than 80% of the members were of Malay descent and Islam was their religious belief, religious support was accompanied by the emotional support. Submitting to the Creator (God) rather than giving up on the child was seen as the ultimate approach for these parents to accept their child as a blessing and not a burden as shown in Figure 4.36. This approach helped to ease the stress of these parents as it made them realised that their child was not a karma or retribution of any sins they had committed. Having a child with ASD was indeed a blessing as it tested the parents' patience and love, not only towards their child but to their spouses and other typically developing children that they had as shown in Figure 4.37.



Figure 4.36. Offering religious support to other parents.

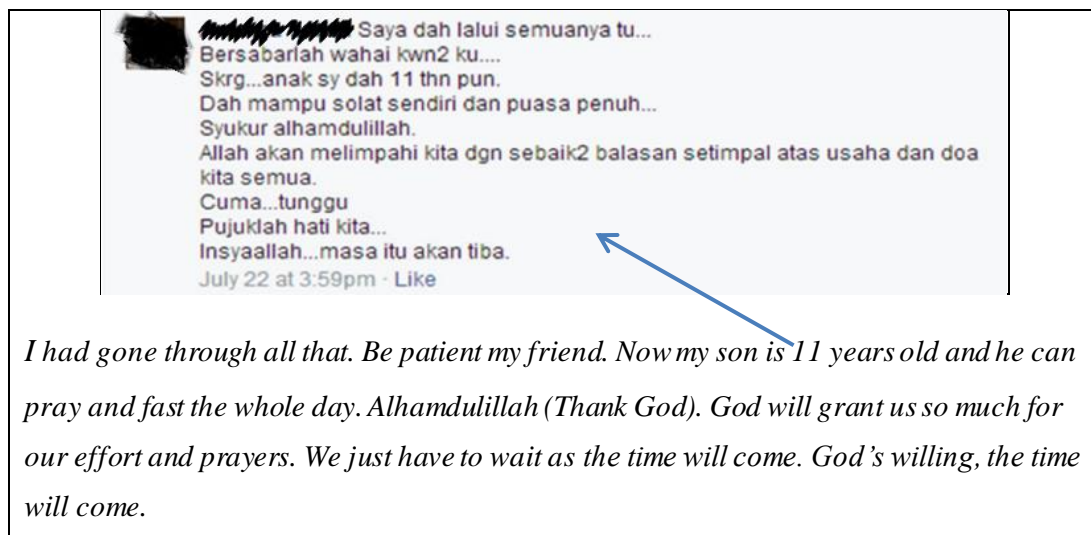


Figure 4.37. Accepting a child with ASD as a blessing from God.

i) How was religious support given?

Religious support usually accompanied emotional support. This approach not only helped to relieve emotional stress but it made parents aware of the purpose of their existence. The words ‘Alhamdulillah’ which meant thankful to God, ‘Insyallah’ (God’s willing), patience and prayers were frequently used to provide religious support to these parents. All the twelve participants agreed that after some time, they began to accept their child as a blessing and worked hard to ensure that the child received the same love and treatment as their siblings. They started to be more positive when helping their child by sending them to therapy and even conducted home therapies on their own. Joining the AM FB support group and becoming highly engaged were some of the initiatives taken by these parents to help their child. The knowledge gained and shared in the Facebook support group was put into good use for the benefit of their child.

One common home therapy that parents regularly did themselves was illustrating social stories. Social stories were used to help their child’s understanding of a social event that was going to take place to prepare their child for a new experience as illustrated in Figure 4.38 and justified by the following interview transcript. Because a child with ASD is prone to tantrums if their daily routine is disturbed, social stories help avoid tantrums. Most

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parents put in the effort to design their own social stories to suit upcoming events because there is a lack of ready-made social stories on the market, particularly in their mother-tongue, Bahasa Malaysia. Thus, these parents would frequently upload their illustrations for others to share with their own children.



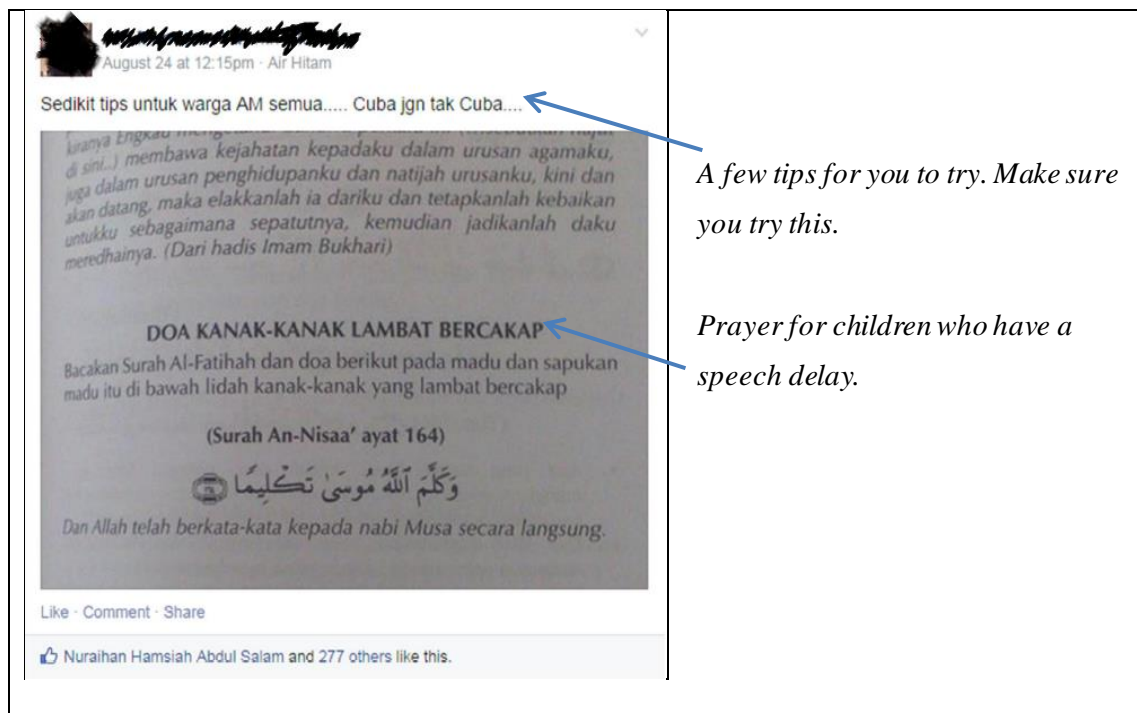
*Previously my daughter always peed and poop in her pants. So, I drew this social story to help with potty training and showed it to her. After a while, she successfully went to the toilet whenever the needs arise.*

Figure 4.38. Sample of social story shared by parent.

“I like drawing social stories using cartoon characters but sometimes I would ask the opinion from other parents on how to go about doing them. It’s not only useful for my son but for me as well”. (NS)

Another way of extending religious support was through prayer and sharing quotes from the Holy Quran. These could be seen as the last resort accompanying the efforts that parents had taken to help their child including therapies and education. Thus, prayers were a last thing that one could do before they left the rest up to God (helping the child). The quotes from the Holy Quran shared by the parents commonly generated more than 150 ‘Likes’ as shown in Figure 4.39 and this indicated the culture of this support group, which was heavily influenced by their religious belief.





*A few tips for you to try. Make sure you try this.*

*Prayer for children who have a speech delay.*

Figure 4.39. Quotes from the Holy Quran.

It seemed that these members found solace for their emotional stress by exchanging religious support and reminding themselves of their existence was like a caliph who would be tested with different challenges. Having a child with ASD was one of those challenges. Thus, religious support was pertinent in the AM FB support group.

### 4.3 Impacts of the three main findings

As illustrated earlier, the three main findings; online engagement, expression of feelings and social support were the distinctive types of communication that emerged in the Autisme Malaysia Facebook support group. These three categories should not be treated as separate entities as they were inter-related. One category led or became the cause of another, for example, parents who engaged in online communication (Facebook) were most likely to express their feelings when communicating with other members. This later led them to seeking support and offering support in return. Parents who started to express their feelings on Facebook and obtained support would become actively engaged in online communication. The act of obtaining support further encouraged them to offer support to others and this

encouraged them to enthusiastically engage in communication on Facebook. As a result, these three categories complement each other and prompted both positive and negative impacts to the parents.

#### 4.3.1 Positive impacts

As expected, participating in online communication on the AM FB support group provided positive benefits to these parents. The positive impacts were further be divided into two categories; impact on the parents as individuals and impact on the parents as members of society, both in online and offline. Table 4.10 below illustrates both the positive impacts.

Table 4.10.

*Positive Impacts of AM FB on Parents*

Parents as individuals	Parents as members of society
<ul style="list-style-type: none"> <li>• Becomes knowledgeable</li> <li>• Becomes emotionally strong</li> <li>• Being selective</li> <li>• Sense of guilt</li> <li>• Sense of relief/ease</li> <li>• Sense of hope</li> <li>• Increased self-esteem</li> <li>• Gaining &amp; giving positive feedback</li> <li>• Preparation for future</li> <li>• Act of noticing/self-realisation</li> <li>• Act of obligation</li> <li>• Putting knowledge into practice</li> <li>• Sacrifices made</li> <li>• Self-determination</li> <li>• Self-value/selfless/self-rewarding</li> <li>• Self-discovery</li> </ul>	<ul style="list-style-type: none"> <li>• Sense of Community Responsibility <ul style="list-style-type: none"> <li>- Sense of belonging</li> <li>- Sense of bonding</li> <li>- Sense of equality</li> <li>- Being influential</li> <li>- Being resourceful</li> <li>- Being understanding</li> <li>- Being respectful to others</li> </ul> </li> <li>• Creating awareness</li> <li>• Application into professional life</li> <li>• Restructuring life</li> <li>• Best platform for ASD</li> </ul>



*Positive impacts on parents as individuals*

i. Become knowledgeable

As discussed earlier, the participants stated that there were some challenges associated with having a child with ASD and their engagement in the AM FB support group made them more knowledgeable. Most parents had no knowledge of ASD and to make matter worse, visits to a doctor resulted in no outcomes either. Joining and participating in the communication on the AM FB support group made these parents more knowledgeable. This knowledge was gained through the experiences shared by other parents, particularly those parents who had a teenage child with ASD. The challenges and ways to deal with them were seen as the most treasured experiences that parents could learn from others. Apart from the parents' experiences, the shared links, which were mostly related to therapies implemented in other countries, motivational quotes, and anecdotes were sources that helped the parents become more knowledgeable. In fact, some parents who read several articles from western countries believed that they were even more knowledgeable than their doctors. This was because some doctors would even ask the parents what ASD was as highlighted in the interview transcript below.

“The truth is doctor never told me about flat feet and low muscle tone. I found about it myself from the internet and I posted to AM FB, then other parents started to look at their own children and realised what I posted was true. All the children have flat feet. That's the symptom of low muscle tone. When I referred to orthopaedics, they didn't know about it”.

(KL)

The knowledge that the parents found very useful were the process and procedures for getting their child diagnosed, sending them for therapies, registering them for school, and practising home therapies. This information was cited as scarce by the parents and not readily available through local councils or any government agencies. The information that these parents shared was either based on their readings or their own experiences, which

made the members trusted them even more than the therapists, as illustrated in Figure 4.40 of the archived Facebook data below. Most therapists, both occupational and speech, would frequently recommend follow-up therapies that parents could practice with their child at home. However, some parents were sceptical of this idea and reluctant to implement follow-up therapies because the therapists did not have a child with ASD. Thus, their expertise and knowledge based on theories were seen as ineffective by these parents. That was the reason these parents put more trust in other parents' knowledge and experiences rather than the therapists'. The following interview transcript illustrates this trust.

"When the professionals (therapists) suggested something that is based on their field..what they intend to convey to you. We may not accept what is being suggested because we learn on our own too. But if parents were to share (tips and suggestions) what they had done, we become more confident to accept what the therapists told us to do". (ND)

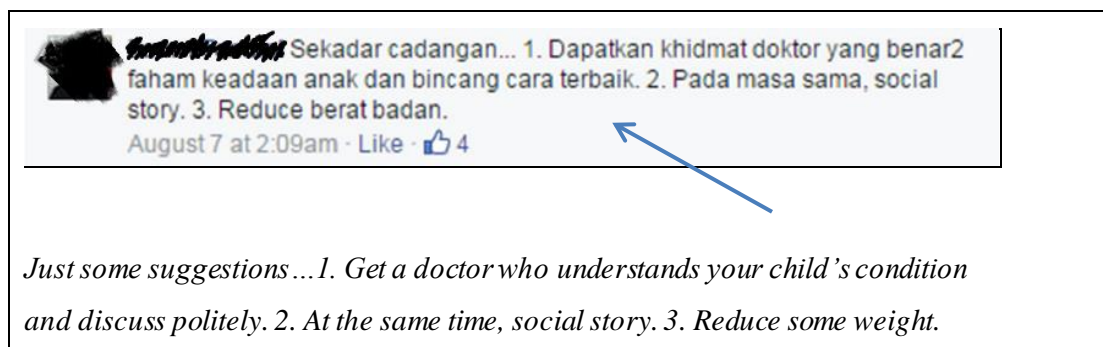


Figure 4.40. Parent giving suggestions to plan for child's circumcision.

### ii. Become emotionally strong

Most participants who joined the AM FB support group started off as *lurkers* or silent readers, reading other parents' status updates. After some time, they became active participants by posting statuses and commenting on others'. This transition was the result of them becoming more knowledgeable and this helped make them emotionally stronger. The knowledge that they gained from the AM FB support group gave them the assurance of what to do, what to expect, and ways that they could help their child. In addition, as discussed earlier, the AM FB was a platform where these parents expressed their feelings as negative

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feelings were the most common feelings being expressed on the AM FB wall (refer Table 1.9). As a result of the support these parents obtained from the Facebook support group, they become emotionally stronger and were able to respond to their child's needs sensibly instead of punishing their child like they did before joining the AM FB group.

The impact of becoming emotionally stronger was very closely related to the sense of guilt, relief and increased self-esteem. Although the sense of guilt seemed to have a negative impact, it was categorised as having a positive impact as guilt triggered the parents to realise their past mistakes when managing their child and promised not to repeat them. Some parents also dwelled on their guilt by blaming themselves for having their child with ASD as shown in Figure 4.41 below and substantiated by the following interview transcript. However, this guilt was quickly brushed aside by other members by sharing similar feelings that they used to have and offering emotional support so that the parents no longer possessed such feelings. All this was achieved through active communication on the AM FB wall.

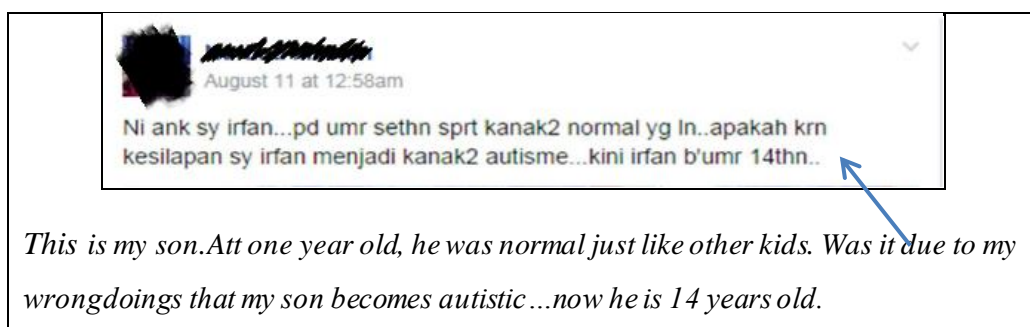


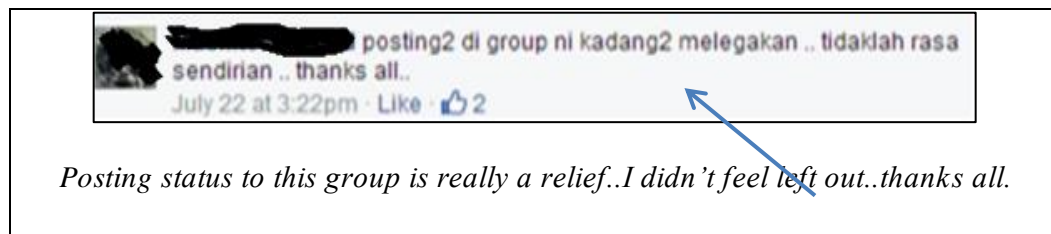
Figure 4.41. Participant dwelled in self-guilt.

"I used to ask for advice on how to treat my child who is naughty as I would normally punish him physically. Then when parents commented that the child (with ASD) should not be treated that way, at that time I was feeling really guilty. I realised that I had made a terrible mistake!" (FH)

Due to the support obtained by the parents from the AM FB group, their sense of guilt or self-blame was finally replaced with a sense of relief as illustrated in Figure 4.42. The act of actively communicating by sharing feelings, struggles, and challenges both

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synchronously and asynchronously, made them felt comfortable as they knew that they were not alone as other parents shared similar experience. Becoming more knowledgeable played a major part in triggering this sense of relief as the parents gained more confidence and increased self-esteem to manage their child.



*Posting status to this group is really a relief..I didn't feel left out..thanks all.*

Figure 4.42. Expressing a sense of relief for communicating in AM FB group.

“When I found AM at that time, I logged in every day, I updated status every day because it’s more of sharing my feelings with others. Then, sharing with people who are similar as I am like Zamri, parents who are in the same shoes... it was a really big relief!” (LW)

### iii. Increased self-esteem

Having a child with ASD posed a great challenge and managing them was a greater challenge. As highlighted previously, most parents would experience emotional stress especially those whose child was between 3 to 7 years of age and who had had not been professionally diagnosed for this disorder. Lacking knowledge on ASD and facing social stigma from immediate family members and the public added to these challenges. This resulted in most parents feeling down and having low self-esteem. Using the AM FB support group as an avenue to channel these feelings, increase the self-esteem of these parents. Not only did they became more ‘immune’ to the social stigma around them, these parents became more confident when taking care of their child as they were aware that they could positively depend on the AM FB members for advice and assistance. This increased self-esteem led parents to share their experiences and extend support to others who were in need. Some would frequently comment on the AM FB *wall* by clarifying parents’ doubt and uncertainty and sharing their blogs, which they specifically dedicated to sharing experiences

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in managing their own child. The links to their blog posts became another platform in which parents could gain knowledge by reading what the parents had gone through and perhaps picked up tips and advice, as cited in the interview transcript below and shown in Figure 4.43.

“Previously, I kept asking myself why is my son behaving like this...but after joining AM FB support group, I become positive, more positive”. (AL)



Figure 4.43. Increased self-esteem led to writing and sharing of blog in AM FB.

Furthermore, the increased self-esteem of the parents helped them face social stigma and implement ways to handle it rationally. Previously, the parents would feel very stressful, sad, and reclusive when faced with the social stigma of having a child with ASD. However, due to the sharing of experiences on the AM FB wall, they became more confident when confronting those who made remarks about their child. Confrontation in this context did not have a negative connotation as these parents would normally confront those people by explaining the disorder that their child had. Some parents even handed out flyers explaining what ASD was. This was one of the ways that these parents used to try to create awareness about ASD among the general public. Social stigma was not only verbal as it was also expressed through the ‘gaze’ usually given to a child who acted aggressively in public. Previously, most parents were too ashamed to bring and expose their child to the public due to this ‘gaze’ but

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

the experiences shared on the AM FB wall by other parents made them more self-confident and proud of their child, despite their disability as shared in Figure 4.44 and explained in the following interview transcript. Most parents put on a ‘poker face’, ignored the ‘gaze’, and enjoyed the time with their child in public places, such as shopping malls, playgrounds, and restaurants.

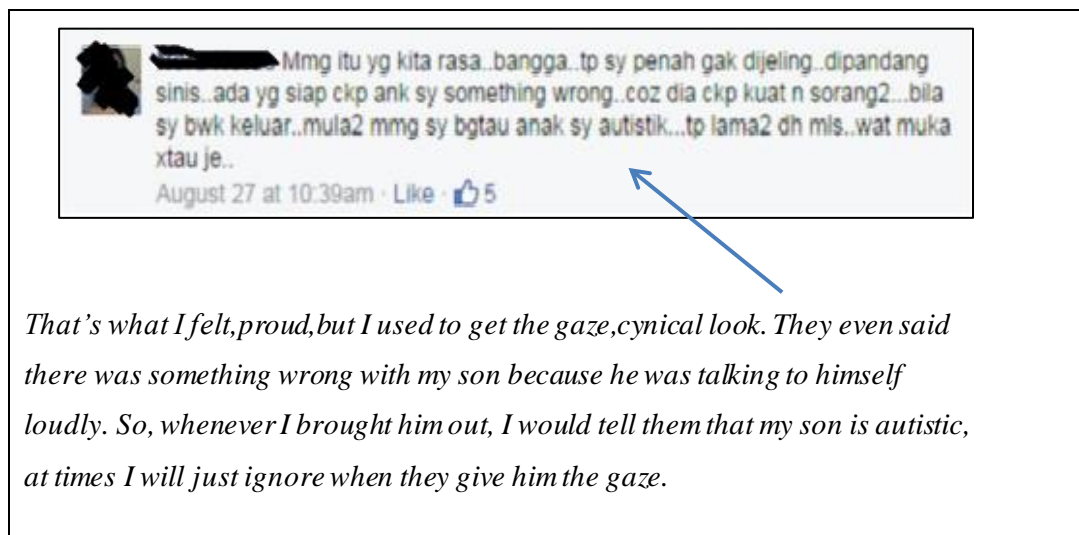


Figure 4.44. Parent ignoring the gaze given by public.

“When parents had the confidence and awareness, they will definitely spread the awareness. When they bring the children out and people give the look, they will explain. God’s willing, they can do it”. (KN)

This increased self-esteem contributed to a sense of hope and preparation for the future that these parents had for their child. The sharing by those parents whose child had become teenagers and adults gave new parents, who just joined the group, a sense of hope that their child could have similar future. New parents could begin making plans on which path that they wanted their child to follow through based on those older parents’ earlier experiences. The new parents found this to be very useful as they had guidance related to where and how to get a diagnosis for their child, which therapies to use and how much was the fees would be, which schools to choose and how to enrol, what home therapies would work and how they could be

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carried out. The parents whose child had passed through these stages had a sense of obligation to share their experiences for these younger and new parents in the AM FB support group. Sharing could be viewed as an act of obligation to help younger and new parents so that they would not go through the struggles when managing their child as illustrated in the interview transcript below.

“That’s why I feel that it’s my duty to help them because they might know about it too late. Sometimes the child is already 9 years old when he/she gets diagnosed. That’s too late. So, if they know earlier, around 4 to 7 years old is a good age to start intervention”. (KL)

“I always share things like home therapies and procedures on how to enrol in school on AM FB wall because I don’t want them to go through what I had experienced before. I don’t want them to struggle like me”. (ND)

This sense of obligation towards helping others was an indication of how support was given to others in the group. This sense was not forced but rather it was a feeling that grew within these parents to help others in need. This feeling might be due to the sacrifices made by these parents when managing their child particularly when their child was still young. In addition, this might also be due to the positive support these parents obtained much earlier when they joined the group and the effect was that they wanted to give the same in return to new parents in the Facebook support group.

The act of noticing or self-realization could be a driving cause and an effect of increased self-esteem. At an earlier stage (before joining the AM FB support group), the parents started to notice and realise something different about their child. However, due to lack of knowledge of the child’s condition, most of them would dismiss the thought that their child was different. After they found and joined the AM FB group, their noticing and self-realising reappeared as they performed a self-

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checklist for their child's symptoms as shown in Figure 4.45 below. This led them to search for more information on the AM FB group and as a result they became more knowledgeable. As discussed earlier, the parents who were more knowledgeable had increased self-esteem and this later enabled them to notice and realise the adjustments that needed to be made with their lives. This was the beginning of the sacrifices made by these parents.

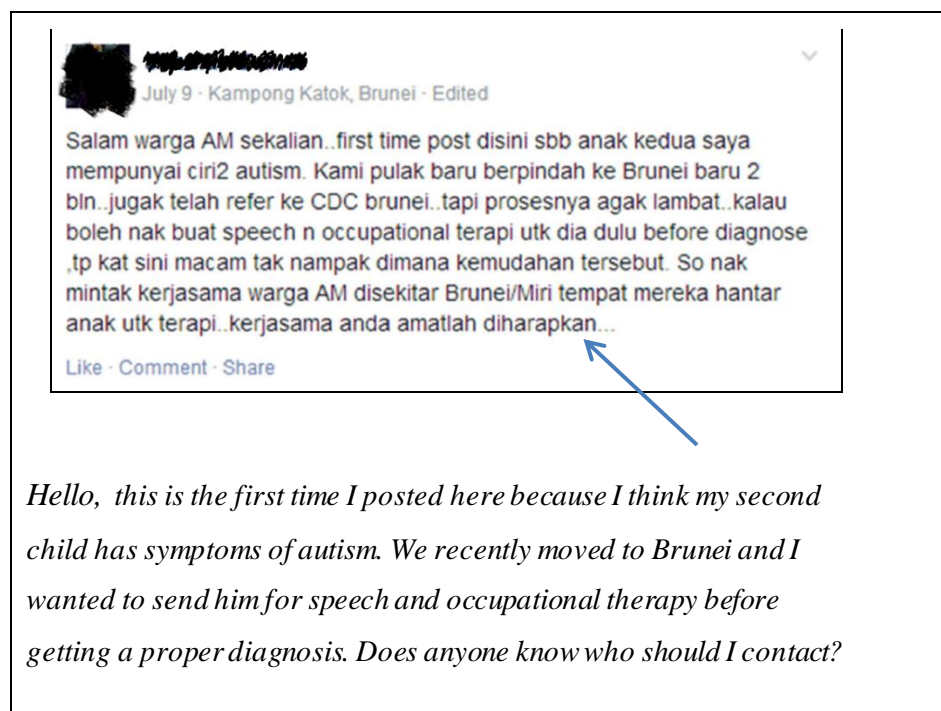


Figure 4.45. Act of noticing by parents.

### iv. Sacrifices made

It seemed that making sacrifices might have negative connotations, but it was categorised as a positive impact as parents made these sacrifices after they accepted and became more knowledgeable about their child's disorder. Sacrifices were made without being forced and feeling depressed as the sacrifices they made were for the benefit of their child. Most parents stated that the sacrifices they made included job arrangements, residential placements and domestic chores.

Job arrangements made by these parents, mostly working mothers, were either to quit their job and become a full-time home-maker or negotiate flexible working hours with



the superiors to fit with the child's school schedule. The former arrangement was adopted by mothers who intended to give full attention to their child, especially those who had children age 2 to 5 who did not attend school. Hours at home were spent carrying out home therapies and taking the child to various therapies including speech and occupational therapies. These were closely related to the domestic chores that these mothers implemented as part of the sacrifices made. For those mothers who chose to continue working after learning about their child's condition, their work schedule was changed by requesting flexible working hours from their superiors. Most of them negotiated working hours with their superiors so that their work schedule would fit with the child's schedule, particularly specific school timetables, as described in the interview transcript below. These job arrangements included flexible working shifts and extended lunch hours. Most superiors, both in the government and the private sectors, were able to make allowances for these working mothers and this indicated compassion and understanding on the part of the superiors.

“Distance from Putrajaya to Cyberjaya is about one hour, so my lunch break is used to pick my son from school and send him home, I don't have time to eat at all. I always eat at 7 pm after my working shift ends”.

However, it was pointed out that not all superiors would agree to these job arrangements, especially those in the private sectors, as there was no national statement or circular that notified them to do so, unlike the situation in the government sectors. Thus, it was up to the discretion of private sector superior if they would allow such practice in their organisations. Due to this discrepancy, some mothers left their job and became either full-time housewives or conducted business from home as illustrated in Figure 4.46 below.

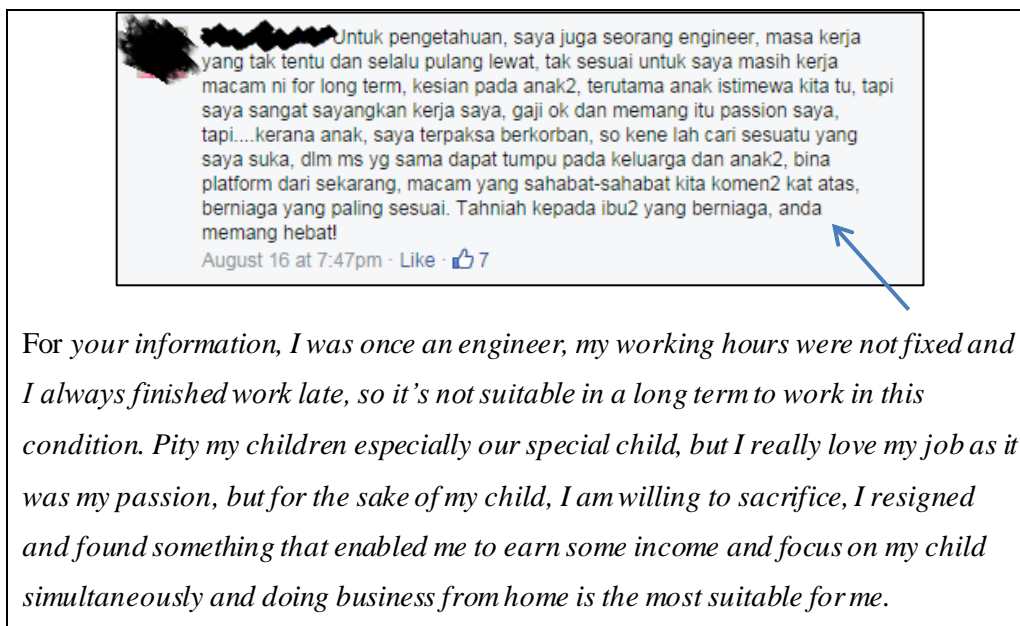


Figure 4.46. A mother narrated her sacrifices.

Another sacrifice made by these parents was residential placements. Some parents decided to move to another state due to the lack of facilities and services in their initial residential areas. Facilities and services including special/inclusive schools, hospitals and therapy centres were mostly found in urban areas, forcing parents to move to these areas so that they could provide the best for their child. Moving to another state meant that these parents had to find new jobs and adapt to a new neighbourhood, which were additional sacrifices that they had to make. However, these sacrifices were seen as benefiting their child as they could access the best facilities and services. The parents also benefitted from face-to-face support group meetings (which was the result of the AM FB support group) that were very active in urban areas. These parents frequently held parenting classes, social outings such as picnics and short trips with the children, and awareness programs. Therefore, these parents could do more by being in urban areas, not just for their child but also for their own selves too.

Domestic chores were cited as one of the sacrifices that these parents made after learning about their child's disorder. As mentioned earlier, mothers who chose to quit their job devoted most of their time to care for their child, but working mothers did the same by

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squeezing in the time required to cater to their child's needs. Most of these domestic chores included carrying out home-therapies, searching and reading articles about ASD on the net, exposing children to public places and organising events for parents and children with ASD. All these were then shared on the AM FB *wall* so that other parents would benefit as well. Most of the home-therapies carried out by the parents were a follow-up or reinforcement of the therapy sessions that their child had with the therapists. In addition, mothers initiated their own home-therapy tools/aids including designing social stories (Figure 4.47) and flash cards, home-made sensory bags, and home-made play-doh. All these were shared on the *wall* especially when their child showed signs of improvement. Again, these chores were carried out due to the love and responsibility that these parents had for their child and this indicated the outcome of the increased self-esteem that these parents gained from the AM FB support group. Increased self-esteem gave them the boost they needed to assist their child whenever possible and this led them to offer support to other parents in the AM FB support group as well.



Figure 4.47. Home-made tools/aids initiated by mothers

The effect of this increased self-esteem could further be seen in parents gaining self-determination, self-value/selfless/self-rewarding and self-discovery.

### v. Self-determination

As parents became more knowledgeable of their child's condition and how to manage it through their active participation in the AM FB support group, their self-esteem increased and made them more confident when assisting their child. This injected them with a sense of self-determination in these parents to provide the best education, therapies, and self-management for their child. As ASD is a disorder with a very wide spectrum, different children require different treatments. Treatment in this context did not refer to a prescribed medication but more to the individualised therapies that suited the needs of each child. Realising this fact, however, parents in the AM FB support group were determined to try out whatever suggestions and ideas were given or tried and tested by other members of the group. Some of the additional therapies that some parents found useful for children with ASD focused on a particular task or calmed their tantrums were swimming lessons and equestrian activities. Although these two activities are quite expensive in Malaysia, the parents were willing to give them a try as other parents had shared their experiences and claimed these activities were effective for their own child. To help a child with excessive energy, which led them to be hyperactive, some parents suggested exposing them to physical outdoor activities such as long-distance cycling and jumping on the trampoline to channel this energy. Again, these parents shared this on the AM FB *wall* and motivated other determined parents to try it with their own child. Sometimes, these therapies worked but other times they did not. This, however, did not deter the self-determination of these parents to seek other alternatives until they found one that suited their child.

“There are things (therapies) that parents did when their children were much older, but I tried with my daughters when they were small, things like outdoor activities. I tried with my daughters when they were 4 while someone did that when the son was 9. Alhamdulillah

(*Thank God*) surprisingly it worked too”. (ND)

Self-determination in these parents was closely linked to feelings of self-value.

Parents realised that they played a big role in managing their child by adapting and changing themselves for the sake of their child. They valued themselves as agents of change and this was achieved by changing their attitude towards their child and adapting their life to the needs of their child. The change of attitude was driven firstly by changing their beliefs that their child did possess a brighter future if an early intervention was introduced. This was due to their active participation in the AM FB support group. As mentioned earlier, reading other parents' statuses particularly those related to their child's achievement, opened up a new perspective and gave these parents hope. Before joining the group, they felt helpless and hopeless as they could not see how they could help their child. Most had almost given up hope when no support was obtained from governmental agencies. Thus, the AM FB support group became the avenue of change for parents' beliefs and attitudes. They started to realise that they played a major role in providing the best for their child as seen in Figure 4.48 and the following interview transcript. Only they, as parents, could steer the path for their child as no one else could be depended on.

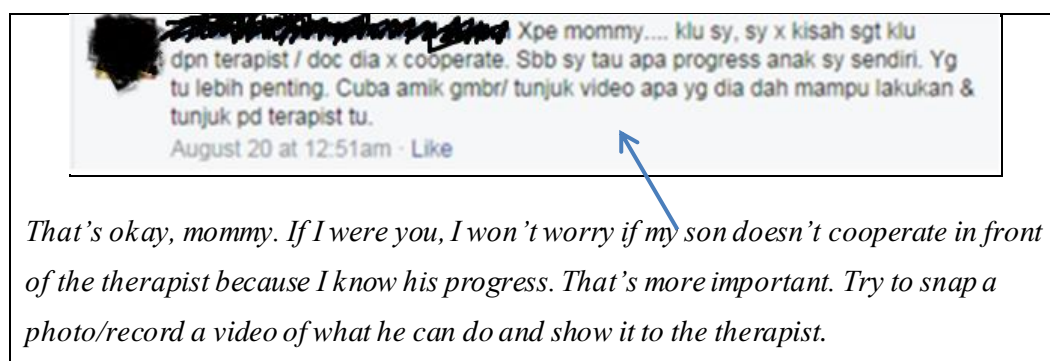


Figure 4.48. Participant's status showing self-determination in helping their child.

"Previously I really have no clue how to help my son. I always told myself that he is a typically developing child just like other children but when I joined AM FB, I realised that all this while I was in self-denial. Joining it has really opened my eyes on how I can help him. So hopefully my son will be positive, just like other children (*in AM FB support group*).

Then we can prepare for his future undertakings". (JB)

When parents were aware of their value, they used it not just to benefit their own child with ASD, but to benefit the AM FB support group as well. They became selfless as all the knowledge they gained by going to parenting classes, therapies, and reading was shared on the AM FB *wall*. They had the belief that this knowledge could be of some benefit, perhaps not to all parents in the group but to some. This was due to the fact that these parents were aware of the wide spectrum of ASD and no two children were the same. This did not discourage them from sharing their knowledge, which might only be useful to some parents. In addition, as members in the AM FB support group were geographically located all over Malaysia, accessibility to knowledge might be limited. Not only were parenting classes and therapies sessions limited, but most articles on ASD were written in English, which could pose another hurdle for these parents. Therefore, parents who were literate in English would share what they had read by translating it to Bahasa Malaysia and posting it to the AM FB *wall*. Other parents with limited English really appreciated and valued this effort. This was how parents in the AM FB support group became selfless individuals.

“So, rather than just reading for my own sake, perhaps I could contribute to the group. I had gone through the stage where my son didn’t know how to hold a pencil, how to go to the toilet and all the stress, so hopefully what I shared is useful to others. I started sharing about the books that I’ve read, some I bought when I was in Japan, through Amazon.com, all

English books from abroad. I note down the methods and translated them to Bahasa Malaysia. The responses from other parents were priceless! They like what I posted and some parents didn’t know how to read in English, so they were really grateful to what I did.

I usually posted about what I read together with the picture of my son because I believe pictures make it easier for others to understand”. (NS)

Another surprising finding, which was closely related to self-determination and self-value, was self-discovery. Self-discovery was significant because these parents discovered more about their own selves after they had learnt about their child’s disorder and had

actively participated in the AM FB support group. Self-discovery is different than self-value in which parents realised their role as an agent of change because self-discovery is geared towards parents understanding their own personality and becoming aware of certain traits. This was achieved as a result of their participation in the AM FB support group. One instance in which this happened was when a mother recognised the attitudes and behaviour that her son with ASD possessed that were similar to her own, as illustrated in Figure 4.49. As she reminisced about her childhood, she became more certain that she had the same experience as her son. In order to confirm of her perception that she too might have ASD, she contacted an expert through the AM FB support group, did her own diagnosis by answering a questionnaire, and the results were positive. This allowed her to learn more about herself and validate her attitudes and behaviours. Her condition was not diagnosed when she was younger due to the lack of knowledge on the part of her parents. This self-discovery made her understand her son even more and allowed her to avoid behaviours that could trigger both herself and her son. She was now even more aware of her surroundings and the triggering factor that could upset her.



Umar.. akak dah tua ni baru tahu akak AS dalam tahun lepas.  
 pengalaman menghadapi hidup tanpa pengetahuan ttg diri sendiri memang sukar... kerana kita dalam dunia kita. Kita memandang sesuatu tu dgn cara tak sama. Kesudahannya... takde yg nak kawan dgn kita... hihhihi  
 tapi kan... mcm yg umar kata... sebenarnya kita lebih beruntung...  
 dan sekarang anak akak pun sama ada dgn akak.. dari dia akak mengenali diri... memang anak autisma ini adalah anugerah.  
 Anugerah terindah.  
 kenal diri. Kenal potensi.  
 inshaAllah.  
 December 5, 2014 at 11:01am · Like · 7

*I'm already old when I found out that I have Asperger last year.  
 Life experience without understanding our own self is really  
 difficult...because we are in our own world. We see things differently from  
 others. As a result, no one wants to be our friend..  
 As you said, we are indeed lucky  
 And now my son is the same as me...I learnt about myself from him...he is*



Figure 4.49. Communicating on AM FB group led to self-discovery.

“I used to be so stressful thinking why no one wants to befriend me when I was at school.

Even now I have very few friends. I stopped schooling when I was in Form 3, I became rebellious and I was different from the others. I also have sensory issues, I don’t like loud noises such as *kompang* and firecrackers, I can simply cry hearing those noises but I don’t know why. But when I found out that I also have ASD, I understand more about myself and also my son. So, now I can control my emotions unlike before”. (KN)

Self-discovery did not only affect the parents relationship with their child but it impacted the parents professionally. This will be discussed in the next section as it was relevant to the findings related to the professional lives of the parents.

### ***Positive impacts on parents as members of society***

The positive impacts of the AM FB support group on the parents was seen through their roles as members of the society. Societies in this context referred to both the online society (AM FB support group) and offline society (general context). Joining and participating in the online society actuated various feelings in these parents. All these feelings were categorised as a sense of community responsibility. There were other sub-headings under this category.

#### **i. Sense of belonging and bonding**

All the parents who were interviewed agreed that they belong to the big AM FB community or society but they preferred to use the term ‘family’. This indicated the close bond that they had with other members and that they saw them as if they were related by blood (familial) even though they might not know all the members of the online society. As part of a ‘family’, they felt they possessed a sense of belonging and bonding to the other



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members. Almost all played their role as individuals who felt responsible for other members of the 'family'. Thus, the sense of belonging and bonding created a healthy environment in the AM FB support group. Some joined other online support groups in addition to the AM, but most of the time was spent with the AM as they felt a strong bond to the group. This might be due to the fact that their sense of bonding was stronger with the AM members.

Figure 4.50 is an example of how this sense of bonding occur when a parent posted a status about another parents' child who was hospitalised. The status garnered 47 Likes and more than 100 comments from members extending their prayers. This was further substantiated by the following interview transcript.



Figure 4.50. An example of sense of bonding in AM FB group.

"I have a lot of 'relatives' in this group (AM FB) unlike other groups. The admins are very friendly and approachable, and always organise various events. All of them are very understanding. Even my own siblings couldn't understand me like those in AM FB support group". (NS)

This sense of belonging and bonding drove these parents to offer help and assistance whenever possible. They might not provide tangible support as in financial or domestic support as it was often, informational and emotional support. When there was a query or request for clarification, they would 'tag' the name of the

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person/people in the AM FB so that those with the expertise could answer. This again showed the sense of belonging and bonding among the members of the group as they could easily identify the people who could offer assistance. The close bonding of these parents was also a contributing factor that encouraged parents to share everything about themselves and their child. All of the twelve participants agreed that they disclosed a lot of information related to their child's condition, feelings, and surroundings on the AM FB *wall*. This was closely related to the sense of ease that these parents when sharing things that happened in their lives. Due to this, the parents treated all members as equal despite perhaps differences in the level of education or socio-economic status. This sense of equality made these parents viewed others the same as they shared one thing in common, having a child with ASD.

“When you post a status, there will be a long thread of members commenting! But if it's something beyond their capabilities to offer help, they would tag the name of the experts and usually, the people being tagged would respond”. (ND)

“All parents in AM are the same. Whenever they are down or the children having trouble at school, they would pour their heart out in AM FB wall”. (AL)

Other themes that were categorised under the sense of community responsibility were acts of being, which included being influential, resourceful, understanding, and respectful to others. Although these seemed to be related to the parents' roles as individuals, these behaviours had an impact on others. Thus, they were categorised as a sense of community responsibility.

### ii. Tagging the ‘otai’

When the participants had been active members for quite some time, they became more experienced and other new members looked up to them. They were mostly known as

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‘otai’ which could be translated as ‘superiors’. These ‘otai’ had influenced members, especially the new ones. They were frequently ‘tagged’ for advice, opinions, and assistance as illustrated in Figure 4.51 below. Their point of view was highly regarded as their previous experiences with their child with ASD became a point of reference for new parents. Their influential views encompassed various topics such as parenting tips, recognising symptoms, workable therapies and the most contentious issue of vaccination. Their influential views could be perceived as either positive or negative but eight of the participants interviewed (who regarded themselves as new parents) came to a consensus that views of the ‘otai’ were always positive and encouraging.



Figure 4.51. Tagging ‘otai’ who could offer help to other parents.

These beliefs were also shared by other parents on the AM FB wall when they expressed thanks and gratefulness for the ‘otai’. These ‘otai’ also acted as mediators, similar to the role of the admins in the group, especially when the issue of vaccination was brought up. Parents, as individuals, had their own opinions and reservations regarding vaccinating their child. This had always been the point used by the ‘otai’ and the admins to alleviate the tension built up when the issue was raised. This could only be achieved when parents in the group practised a sense of community responsibility by being respectful to others.

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“For me, I could recognise my first daughter is similar to whose children, same goes with my second daughter. So, whenever that parents post a status about their children, I will pay extra attention. If they posted about an effective therapy, I will do it as well because that’s a living proof “. (ND)

Being respectful to others was embedded in the group’s terms written on the AM FB *wall* and quite frequently, members were reminded of these terms by the admins of the group, particularly when the members were involved in a heated debate. Most members did abide by the rules as most of the time the responses to the posted status were positive comments. This could be an indication of the harmonious environment the members created in the support group. Being respectful was closely related to being understanding as when parents understood each other’s challenges they would have respect for the individuals. This respect was further maintained by these parents as eight of the participants claimed that they preferred to reserve their comments rather than writing them on the comment thread if they felt that a status posted would create a heated debate. The other four participants were the admins and therefore they had to act as mediators by providing a more neutral view on the issue.

“I usually just read it (a controversial issue) but not going to give a comment or click on Like. I don’t want to get involved as everyone has their own opinions. You have to be open-minded to other people’s opinion and you digest and make your own decision. We respect their decision and so please respect our as well. (FH)

As discussed earlier, most of the ‘otai’ became point of references and were resourceful people. Their vast knowledge and experiences were easily accepted by other parents in the group as resources. Other parents (both old and new members) were involved in the online activities on the AM FB by sharing links related to ASD, which made these parents additional resources. Several links lead to websites that mostly originated from western countries. They consisted of numerous topics such as therapies, diagnosis, and

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supporting families of children with ASD. The links came in the form of the website addresses, online articles, visuals, and words of wisdom. Facebook allowed this sharing features that made linking and sharing to the AM FB *wall* accessible and feasible. Some parents even shared audio-visuals in a form of videos which were very relevant in assisting others to easily understand the content of what was written in the status. Figure 4.52 showed some of the links shared by the parents on the AM FB *wall*. The sharing of links on the *wall* was one way in which parents acted as members of the online society by creating awareness among each other.



Figure 4.52. Parent sharing links related to ASD.

### iii. Creating awareness

Some parents, especially the newer members, may not have been aware of the latest updates related to ASD issues. An update on the list of schools for special or inclusive education, new EIP and therapies centres, and the latest methods of therapies were some of the issues that parents might have missed. In addition, they might miss on the most important thing that could affect their child's welfare, such as a government circular. By sharing related links on the AM FB *wall*, all parents regardless of where they might be, would be able to get the information. One good example was when the government put out a circular directing parents of a child with disabilities holding a disability card (known as OKU in Malaysia) to change it to a new pink card. If this was not done within a given date,

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the child's schooling allowance would have been affected. This information was shared by a parent on the *wall* and generated hundreds of comments by other parents stating that they were not aware of this new ruling as illustrated in Figure 4.53 below. This showed that the sharing of relevant links was pivotal in creating awareness among parents in the online support group.

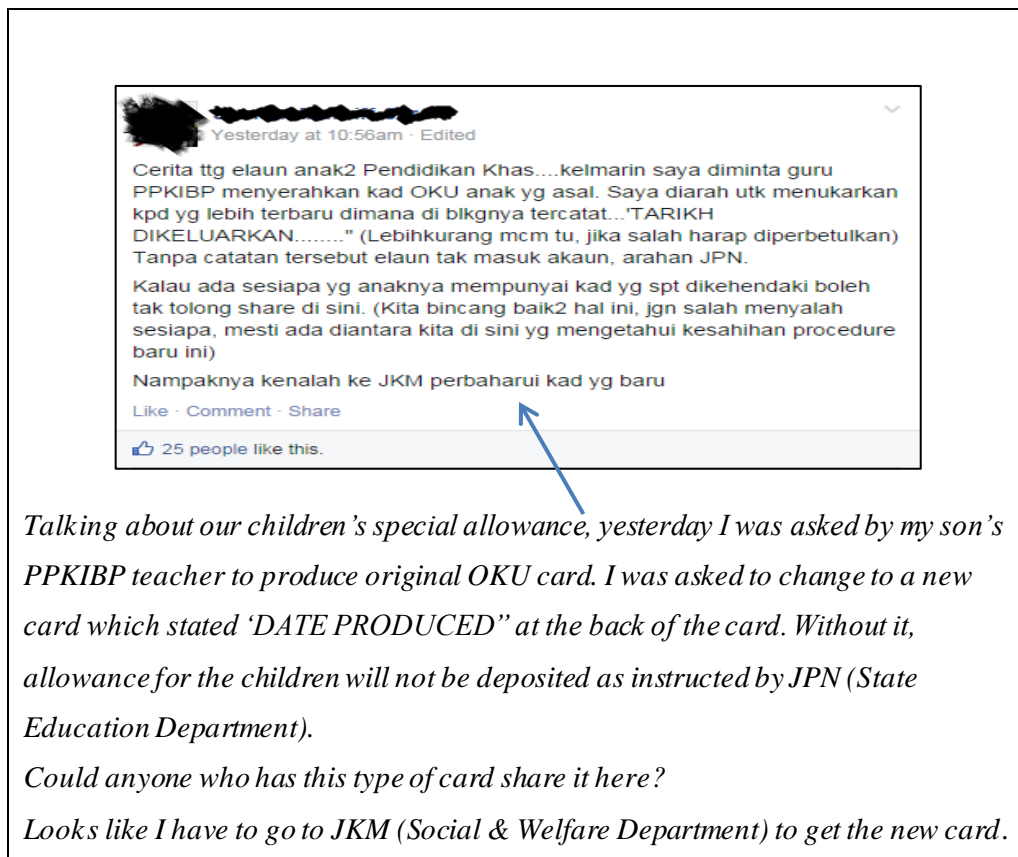


Figure 4.53. Creating awareness in AM FB regarding new government ruling.

The responsibility for creating awareness was further enhanced when the AM FB support group's setting was changed to a Public Group that allowed the general public to access the group. Without joining the FB group as a member, the general public could now read what was being posted on the *wall*. This was a way for the members of the group to create awareness of ASD among the general public in Malaysia. As awareness of ASD was still considered low among Malaysians, as evident in the social stigma of people labelling children with ASD as mentally retarded, making the FB group a Public Group was an excellent move. This meant that people outside the FB group could read and gain knowledge

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about ASD. Eleven participants lauded this move to create awareness except for one who believed the group should be made a Close Group or private. This was because the content of a status, especially when it involved personal feelings, was considered very private for this participant. At times when other parents were criticising special education teachers or schools, it might create discomfort among the general public. However, this opinion was later dismissed by the participant when she realised that making the AM FB a Public Group would bring more benefits than disadvantages.

### iv. Application to professional life

As described earlier under the topic of self-determination, self-discovery also had an effect on the professional life of these parents. In this context, the participants' self-discovery had a great impact on society through the job that they held. One good example was a participant (father) who worked as a policeman claimed that participating in the AM FB had made him more aware of his son and this in turn had changed his way of dealing with others, particularly the line of duty. The awareness that he obtained from the AM FB support group about ASD not only benefitted his son but it also benefitted the public in general. This was because it had transformed the way he dealt with 'troublemakers' compared to before he was aware of ASD. As a result, his action in dealing with such cases had instilled some awareness among his colleagues. This indicated an indirect role played by this parent as a member of the offline society (for the general public). This is shown in the interview transcript below.

“What I obtained from AM FB had changed myself a lot. My views of others have changed as my job requires me to encounter with the public most of the time. Sometimes when I received an order to go and check out on troublemakers, when I arrived at the scene, I can easily identify that the persons have issues (disabled). Then, I will ask the persons gently because I know the reason they created a scene is to get attention. They would usually respond favourably. So when my colleagues watch how I treat these troublemakers, they

were wondering why. That's when I will explain to them so that they become more knowledgeable". (LW)

#### 4.3.2 Negative impacts of the AM FB support group

It was a shocking finding that a support group could also have a negative impact on its members. Although the negative impacts might not dominate the positive impacts, their presence could affect the participation of the members in the long run. Table 4.11 shows the types of negative impacts found in both the archived Facebook data and the interview transcripts.

Table 4.11.

##### *Negative Impacts of Communicating on the AM FB Group*

Themes	No of occurrences
• Negative perceptions	13
• Obstructed freedom of speech	8
• Acceptance of others' xxx behaviour	7
• Being cautious	8
• Easy way out	4
• Expressing doubt	5
• Finding alternatives	7
• Hurtful comments	10
• Recurring topics in AM FB	2

##### *Negative perceptions*

Negative perceptions were the most common type of negative impact in the AM FB support group. A Facebook *wall* is a form of written online communication, which can be the cause for negative perceptions to occur among members. The members rely solely on written communication, which lacks all the features of verbal communication and they can easily misinterpret the message that the writer was



trying to convey. All twelve participants agreed that some parents had negative perceptions of things being posted on the AM FB wall. This was indicated by the negative comments that at times sparked an argument on the comment thread and the members began to criticise and condemn each other. Some even resorted to a personal attack by criticising the member openly on the wall. Figure 4.54 is an example of members using a personal attack on the AM FB wall. This was a moment when the admins would interfere by asking the members to remain calm and rational and reminded them of the rules of the group, which was to respect others' opinion. If the heated argument continued, the status would be deleted by the admins as the last resort as highlighted in the interview transcript below.

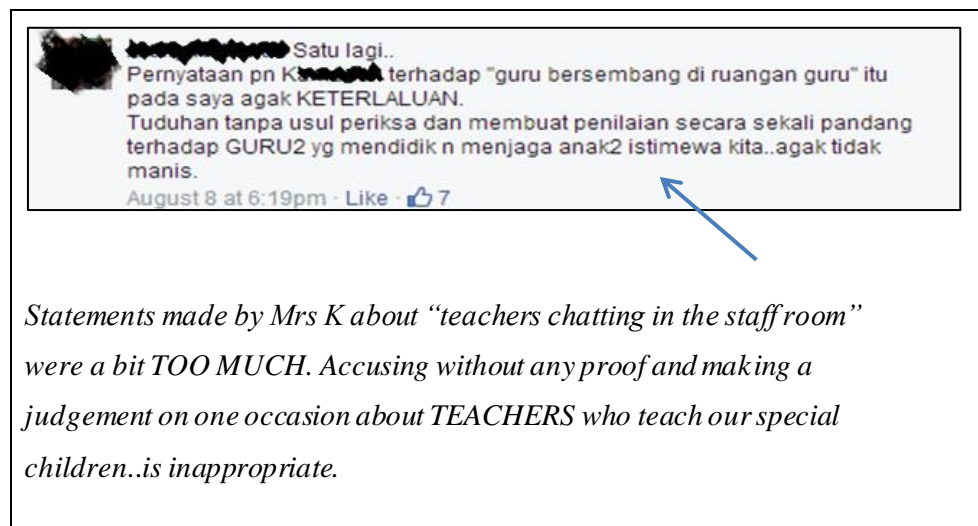


Figure 4.54. Comment made showing personal attack.

"Admin has to do that, admin acts as a peacekeeper. If things get worse, we have to delete the posts because we don't want to create tense in the group. Normally when members read the post although the post is not directed to them, they could become offended too. So, this creates a negative vibe in the group. So, the admin has to take action by deleting the post".

(MA, one of the admins)

At times, a status was shared to highlight the world-class achievement of a person with ASD and this could also cause negative perceptions among the members.

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Instead of looking at the positive side of the status, these parents preferred to find fault in the person. One very good example was the status on the achievement of Lionel Messi, the famous Barcelona footballer. Despite having ASD, he had proven that he could be successful in his chosen field. This fact was not celebrated by all the members in the AM FB support group as some resorted to giving negative comments on him being a Jewish and supported Israeli's occupation of Palestine. To make matter worse, these negative comments spawned quite a number of 'Likes' which indicated that other parents (who might not be commenting openly on the wall), supported them. As most Malaysians' Muslim loathed the conflict that happened between Israel and Palestine, this had influenced those members to bring up the issue on the AM FB *wall*. Thus, it seemed that the parent who shared the status was in a way condoning what Israel had done. As a resolution to end the negative perception of those members, the parent who posted the status had to clear the air by explaining her initial intention of sharing the post and dismissing all the negative comments. Figure 4.55 below shows the status and the negative comments made by some of the parents while the following interview transcript provides an explanation by the parent who posted the status.



Figure 4.55. A status shared on AM FB wall that sparked debate.

“I used to create controversy when I posted on Messi. I was so frustrated reading the comments that I finally replied (on the wall) that I was not highlighting him as a Jewish or supporter of Israel! For me, regardless of who he is, him being autistic was able to become a famous footballer. People all over the world are proud of him! He went through all the odds of ASD to become who he is today and that is what we should emulate”. (KL)

Thus, negative perceptions could be associated with hurtful comments as most of the hurtful comments were a result of the negative perceptions held by the

members. There those who audaciously expressed their negative perceptions openly on the *wall* by writing hurtful comments while others chose to be more 'secretive' by sending a private message to the parents. However, there were also those who preferred to remain silent readers and restrained themselves from making comments although they did not agree with the status posted on the *wall*. This was one way they acted cautiously as the members who frequently sparked a heated argument or commented negatively were removed and banned from the AM FB support group by the admins. This would only be implemented after few warnings had been given to the members and if the behaviour persisted. This action, however, was seen by some members as obstructing their freedom of speech on the group's *wall*.

### ***Obstructed freedom of speech***

Following the theme of negative perceptions above, the members who had been given warnings by the admins, faced the possibility of being removed and banned from the group and they felt that their freedom of speech was being obstructed. As an Open Group, members should be free to express what they felt on issues being raised. When a Facebook group is put on the Open Group setting, it means that everyone should have access to read and comment on the *wall*. The comments could either be positive or negative as these would not break the terms and conditions of Facebook. However, members of the AM FB must be aware that the AM FB support group had its own admins who monitored their activities and it was stated clearly in the rules of the AM FB group that negative comments or statuses that sparked heated argument faced the possibility of being removed as can be seen in Figure 4.56 below. Removal started with the comments or statuses being removed and then the members would be removed from the support group if they did not change their behaviour. The 'Remove' feature in FB still allows the support group *wall* to be visible to the parents who had been removed, but they could not

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post or conduct any online activities such as posting a status, commenting, Liking or Sharing a post.

August 7 at 12:58am

Assalamualaikum dan salam sejahtera.

Ahli FB AM yang dihormati. Untuk makluman semua, saya ialah pengasas group AM dan juga salah seorang dari 16 orang Admin group ini. Group ini ditubuhkan adalah dengan tujuan menyediakan platform untuk berkongsi apa sahaja yang berkaitan dengan autisme bagi manfaat komuniti autisme & masyarakat Malaysia. Bagaimanapun, Admin telah menggariskan etika-etika sebagai langkah

1. menjaga keharmonian.
2. mengelakkan menjadi tempat lubuk duit oleh pihak yang tidak bertanggungjawab.
3. supaya tidak keluar dari matlamat asal AM ditubuhkan.

Sila rujuk di ruang Files bagi menyemak etika-etika dan panduan yang telah digariskan.

Etika Autisme Malaysia.  
<https://www.facebook.com/notes/autisme-malaysia/etika-autisme-malaysia/10150764825883069>

Panduan Khusus Untuk Penyedia Perkhidmatan/Pembekal.  
<https://www.facebook.com/notes/autisme-malaysia/panduan-kepada-pembekal-produk-dan-pemberi-perkhidmatan/10152417872468069>

FB AM bukanlah group yang berorientasikan perniagaan atau keuntungan. Bagaimanapun, Admin membenarkan penyedia perkhidmatan dan pembekal yang berkaitan dengan autisme untuk mengiklankan perkhidmatan (merujuk kepada khidmat terapi/rawatan oleh individu atau organisasi) dan barangan (merujuk kepada sebarang produk kesihatan, ubatan/supplement, alat permainan/terapi), namun masih tertakluk kepada etika yang telah digariskan.

Ada pihak memberikan maklumbalas kepada Admin dengan mengatakan Admin mengamalkan pilih kasih dalam polisinya. Admin ingin menegaskan bahawa Admin tiada pilih kasih dalam melaksanakan polisinya. Admin secara berkala ada mengumumkan peringatan terutama kepada ahli-ahli baru agar mereka sedar adanya etika di dalam AM.

Saya bagi pihak Admin memohon maaf sekiranya ada pihak yang merasakan tindakan kami dilihat sebagai pilih kasih. Dan Admin menggalakkan semua ahli mengamalkan 'self-regulation' dan etika baik/positif media sosial bila menggunakan FB AM.

Wasalam.

ps: Sila berhubung dengan admin Zamri Tembol / Hasfizar Mukhtar / Zaini Abas bagi mendapatkan kebenaran mengiklan.

Like · Comment · Share

👍 Nora Yusof and 92 others like this.

*Dear respected AM FB members. For your information, I am the founder of AM FB group who is also one of the 16 admins here. This group was set up as a platform with the aim of sharing anything related to autism for the benefits of autism group specifically and Malaysia society at large.*

*However, there are some guidelines that we have outlined for you to follow to ensure*

- 1) group's harmony*
- 2) this group is not a place for people to take advantages (by selling irrelevant things)*
- 3) members do not steer away from the main purpose of the AM FB group*

*Please refer to Files section for the rules and regulations.*

*Ethics of Autisme Malaysia*

*Specific guidelines to those who sell related products.*

*AM FB is not a group that is based on business or profit. However, admins allow those who offer services or products related to autism to advertise here (therapy service by individual or organisation) and products (supplements, toys, therapy equipment), but you have to adhere to the guidelines given.*

*I have received feedback from some*

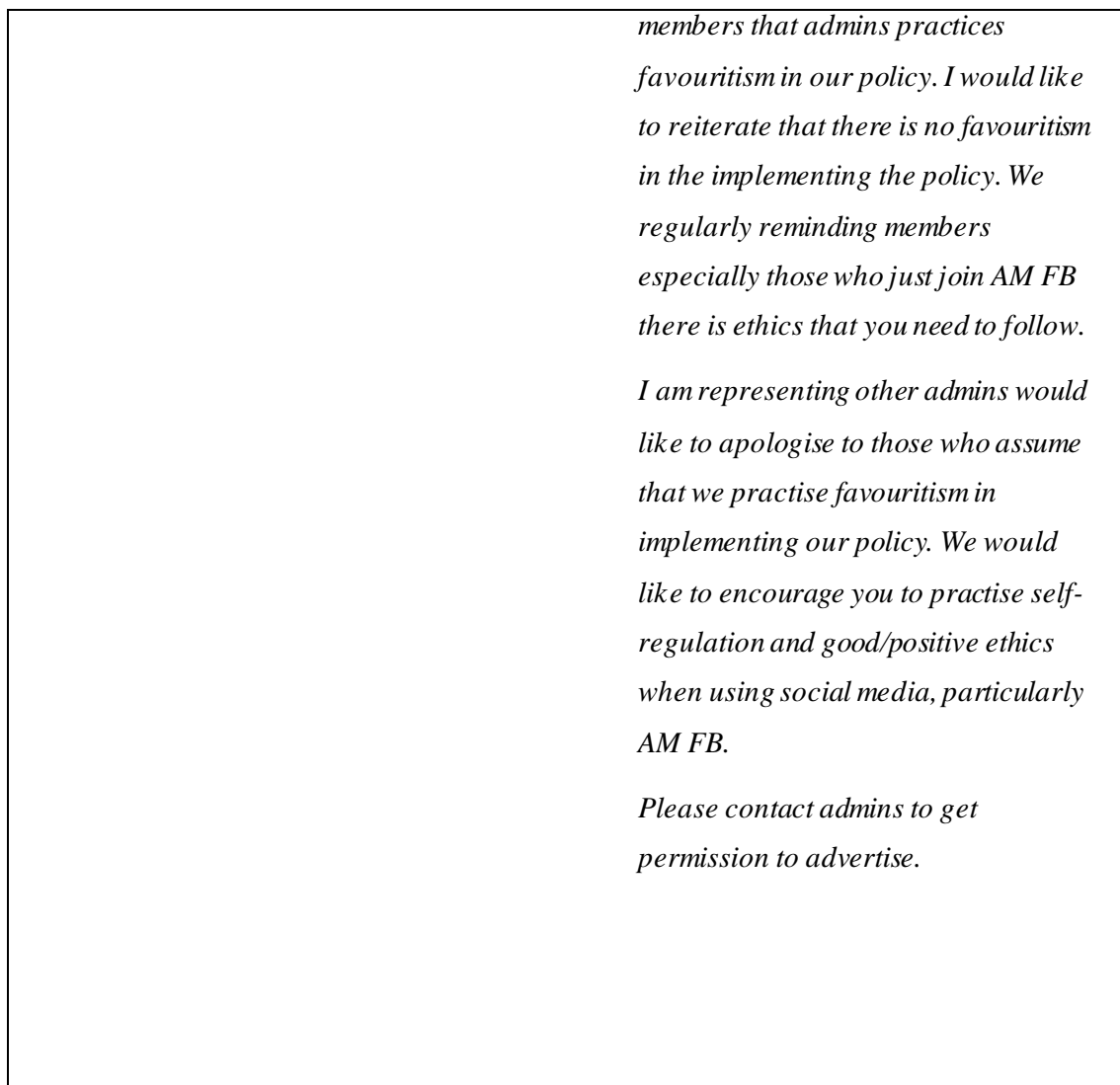


Figure 4.56. Admin reminding members to adhere to the rules of the group.

Although the rules seemed to be rather authoritarian, all the four participants who were admins claimed that the rules were necessary to maintain the harmonious environment in the AM FB group. They believed that the negative vibes brought by certain members could have an adverse effect on other parents and this might result in more emotional stress among the members. Members had enough emotional stress related to managing their child and their lives, thus another contributing factor of emotional stress was not needed. This opinion was also shared by the other eight participants as they believed that the negative vibes in the support group did more harm than good as the main purpose of joining the group was to get support and not to add to the challenges that they already had. One parent who joined other Facebook

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support groups from other countries claimed that the admins of those groups were even sterner compared to the AM FB admins as seen in the interview transcript below. Figure 4.57 is an example of a parent who felt their freedom of speech was obstructed that led the parent to post such a status.

“In my opinion, this is one of the best group (AM FB) in Malaysia. I joined two or three FB groups on ASD which are based abroad and also one in Malaysia called Kelab Kanak2 Autism Malaysia but the *wall* seems to be quiet because the admins control the post. When we post a status, the admins will hold it and they go through it before putting the status on the *wall*. Only then we can see the status”. (NS)

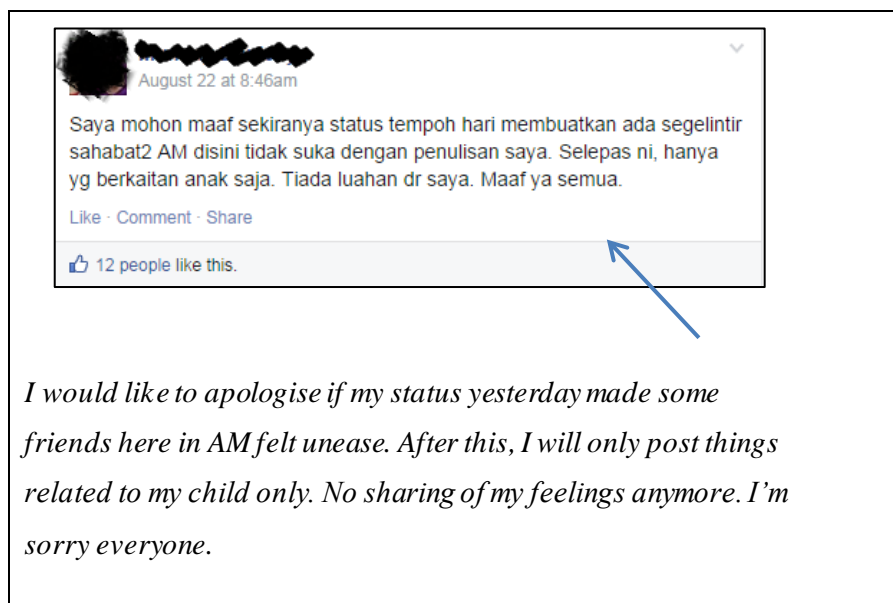


Figure 4.57. An example of status implying obstructed freedom of speech

### ***Finding alternatives***

Finding alternatives might seem to have a positive impact to these parents participating in the AM FB support group. However, this theme was categorised as having a negative impact as the members who posted questions asking for alternatives frequently asked if there was an easy cure for ASD. These alternatives included supplements, homeopathy treatments, and tools. Those in related businesses often discussed the cause of ASD and how their supplements and homeopathic

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treatments were successful in ‘curing’ ASD. Those parents, who were vulnerable, would share this on the AM FB *wall* and fall into the trap of believing these stories. All the twelve participants agreed that they considered this a trap as most of the supplements and homeopathic treatments were not medically tested and approved for ‘curing’ ASD. In fact, the cause of ASD is still vague and cannot be proven medically. Thus, it is even more impossible to find a ‘cure’ as there is no ‘cure’ for ASD. The only tested and approved techniques are therapies that help parents and children with ASD managing their education and behaviour. However, the parents in the AM FB group were always reminded that due to the wide spectrum of ASD, some therapies might not work on their child. Therefore, they were encouraged to try out those therapies and determined which one worked best for their child. When it came to the supplements and homeopathic treatments, they should not fall prey to these non-medically proven business strategies. Figure 4.58 shows parent sharing medical alternatives, which might not be clinically-tested and proven.



Figure 4.58. Link shared on alternative ‘cure’ for ASD.

One way to avoid this type of negative impact in the AM FB support group was by ruling out those who wanted to advertise products or services. They must obtain permission from the admins before posting them on the *wall*. This was clearly stated in the rules of the group and members were regularly reminded. Only after permission was granted to the member, could they post their business and this was



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limited to business pertaining to ASD only for the benefits of the members. Other businesses were not allowed as excessive businesses advertisement on the *wall* did not serve the purpose of this Facebook support group and such posts were deleted as shown in Figure 4.59 below.

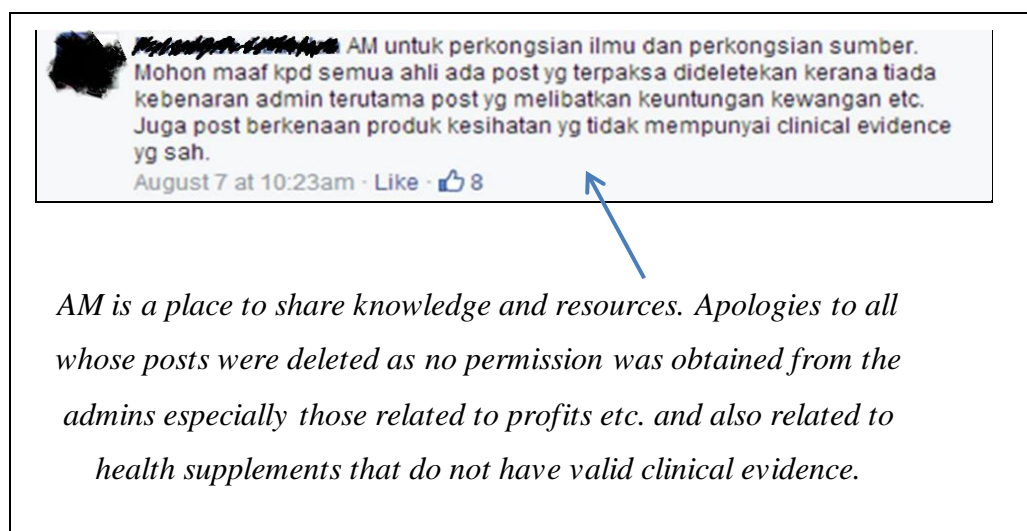


Figure 4.59. Reminder of posts being deleted.

### 4.4 Discourse analysis

#### 4.4.1 Narrative discourse

The third sub-question for the second objective of this study investigated the discourse dominant in the AM Facebook communication. As expected, the narrative discourse was pertinent to parents in the AM FB support group *wall* as they used story-telling to share feelings and stories about their personal life. Most participants who posted to the AM FB *wall* usually wrote a narrative about their child before moving on to seeking support. The narrative was frequently about their child's condition and behaviour (social, tantrum), educational matters (school and policies), medical-related matters (diagnosis, therapies) and governmental-related matters (registration, working parents' policies). Figure 4.60 illustrates an example of narrative discourse used by a mother to share a story about her son. She started off by describing what her son did, the social stigma from his friends, how she responded to such stigma, and finally, words of self-motivation. It seemed that this

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mother was imperceptibly seeking advice on how to address social stigma and managing her emotional well-being. This was not clearly written but most parents in the AM FB support group would comment by giving suggestions and emotional support to this mother. There were also those who complimented her son for being brave in supporting Al-Qassam, the controversial regime.


<p><i>Assalamualaikum and good day everyone...</i></p> <p><i>I haven't posted anything here for quite some time. I have been busy. I haven't regained my spirit to write..hehehe (giggle).</i></p> <p><i>Nowadays Aiman is obsessed with al-Qassam. He does feel like a warrior. Yesterday he told me that he wanted to die as a shahid.</i></p> <p><i>He has been wearing the same outfit for two days and refused to change. Other kids have been teasing him, not just the small kids..bigger kids too! Our people really love to tease, don't they?..</i></p> <p><i>He always ignores my advice. Yesterday I reprimanded those bigger kids..but kids nowadays, they don't care let alone to respect us as elders. I was also being teased, pity me..hehehe (giggle).</i></p> <p><i>I just don't know..hopefully, I will be stronger in facing all challenges.</i></p> <p><i>Thank you.</i></p> <p><i>(KN)</i></p>	<p>Self-explanation</p> <p>Child's social behaviour</p> <p>Expressing disappointment</p> <p>Feeling hopeless but instilling self-motivation (a subtle way of seeking support)</p>
	

Figure 4.60. Sample of narrative discourse posted by participant

### 4.4.2 Discursive struggles

Using the relational-dialectic approach to discourse analysis, discursive struggles were critical in the narratives of these parents in the AM FB support group. The archived Facebook data revealed two prominent discursive struggles faced by these parents, *disclosure vs. discretion* and *self-help vs. helping others*. This finding was further supported and confirmed through the interviews as to the ways these contradictions were tolerated and managed. These illustrated how they could maintain a healthy and lasting relationship within the Facebook support group. The relationship in this context denoted the mutual understanding that each member who joined the group had the same purpose, which was to seek, obtain and extend social support within the group.

#### *Disclosure vs. discretion*

In the context of social media such as Facebook, disclosure is an issue that users should be aware of. The amount of information being disclosed on social media was determined by the users as the information was easily shared by any third party without asking for the user's consent. Under the topic of disclosure vs discretion, there were three sub-topics of discourse: (i) discourse of child's achievement; (ii) discourse of spousal relationship; and (iii) discourse of social stigma. All three discourses contributed to the discursive struggles that these parents faced when using the AM FB support group.

##### i) Discourse of a child's achievement

Most parents chose to disclose details related to their child, such as parenting, behaviour, routines, education and therapies. They frequently disclosed these in the form of narratives and posted them on the Facebook *wall*. The narratives generally described the child's achievements, which may have been very small, but that indicated the child's progress. Sharing it with other parents on the AM FB *wall* was one way to celebrate small

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victories for the parents, and consequently, might offer hope to other parents that their child could achieve the same. This was how social support was communicated in the AM FB group. However, some parents in the group misinterpreted the message that these parents tried to convey (who posted about the child's achievement) as being boastful and bragging of their child's achievement. Instead of looking at it as the extension of support, they felt hopeless as their own child had yet to achieve as much as other children. Figure 4.61 below illustrates a status posted by a participant sharing their child's achievement and offering hope to others.



Figure 4.61. Status illustrating discourse of child's achievement.

It can be seen from the post that the participant had politely reminded the other parents not to expect too much from their child with ASD. The repetition of the word 'special' was an indication that perfection was almost impossible due to the disorder. Thus, parents were gently reminded that a small step by their child was a giant leap for the parents and it needed to be celebrated accordingly. This post might look inoffensive but the parent who posted the status was faced with the discursive struggle of disclosure vs discretion. The disclosure vs discretion struggle was caused by other parents in the group who were

unhappy with the post and expressed their displeasure through private message. The interview transcript below shows the responses that this parent received through *pm* on her FB page.

The truth is whenever I posted about my son on the wall, there were parents who were dissatisfied, pm me and said I wanted to boast about how great my son was! There were also parents who said, “Could you not post so much about your son on the wall”? (KL)

Thus, this parent was in a dilemma and caught between whether she should disclose the achievements of her child or be discreet and not share any more narratives on the AM FB *wall*. To explain her initial intention behind posting her status, she had to respond to the comment thread on her status by enlightening other parents that this sharing was meant to offer social support so that others would not give up hope for their child and strive to help their child whenever possible. This was the strategy used by this parent to ease the discursive struggle that she faced.

### ii) Discourse of spousal relationship

The second discourse pertinent on the AM FB *wall* that sparked discursive struggle was discourse related to spousal relationships. As most of the AM FB support group members were mothers of a child with ASD, they tended to disclose the challenges and struggles they faced with their spouse. This was frequently narrated and shared on the AM FB *wall* where they lamented their sadness and disappointment over their spouses' reaction towards their child. Most of these narratives illustrated that the fathers did not accept or were in denial about having a child with ASD and this consequently affected the relationships between the father and the child and the husband and wife. The status in Figure 4.62 below shows a narrative of such a struggle.

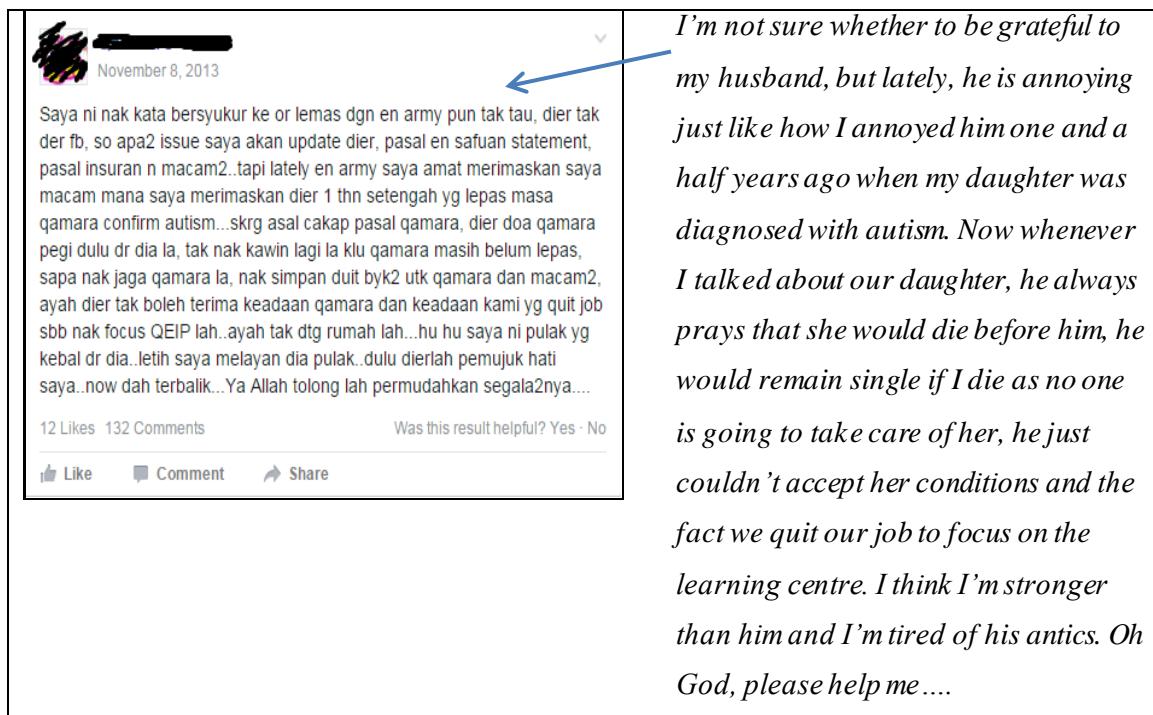
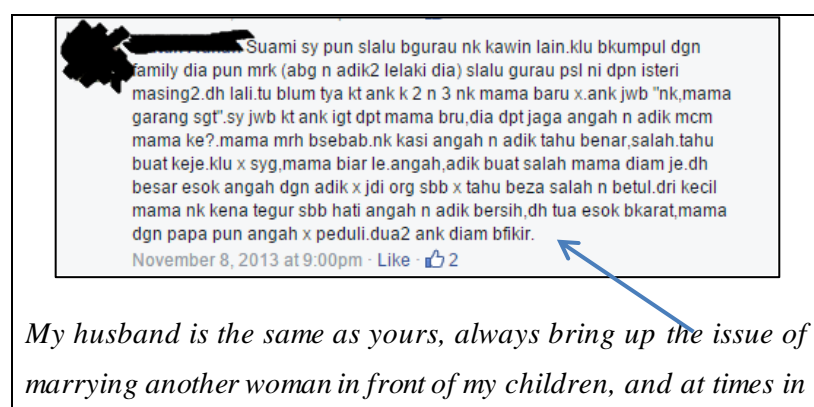


Figure 4.62. Status illustrating discourse of spousal relationship.

The 132 comments generated by this post indicated the high level of responses from the members. In this example, the discursive struggle occurred not through private messaging but through the comments made by others in the comment thread of the status. Generally, there were two positions expressed in the comments; one that supported the wife and one that did not. Those who supported and agreed with the wife commented by sharing similar experiences that they had with their own spouses, as can be seen in Figure 4.63. Those who did not support these type of status being shared on the AM FB wall responded by advising the wife to be more discreet when it came to her spousal relationship (refer to Figure 4.64).



*front of his family members (his siblings).*

Figure 4.63. Comment made to support the wife's status.

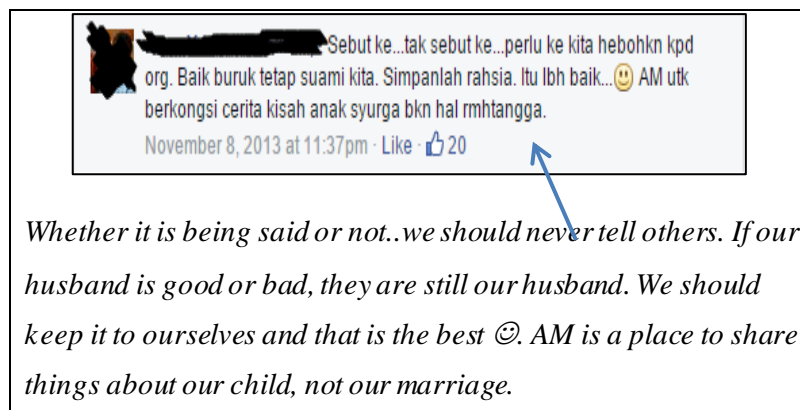


Figure 4.64. Comment made to not support the wife's status.

These contradictory comments made by members show how a discursive struggle occurred in the AM FB group. Spousal relationships are sacred in Malay culture and most of the members in this Facebook support group were Malays. The culture calls for both the husband and wife to be discreet about anything that happens in their married life and it should not be shared even among immediate family members. It was viewed as ethically and morally wrong to tell others about the problems in your spousal relationship, and even worse to tell it to 'strangers' such as those on the FB *wall*. It seemed that they were hanging their dirty linen if they ever shared their struggles. That perhaps could explain such response in Figure 4.63. Thus, to ease this discursive struggle, other parents participated in the comment thread by dissipating the tense atmosphere by changing the subject being discussed. In this instance, it could be seen that other members could identify the discursive struggle occurring on the FB *wall* and they acted as peace-makers.

### iii) Discourse of social stigma

The discourse of social stigma was another prominent discourse evident on the AM FB *wall*. Having a child with ASD can attract social stigma from the general public and even immediate family members. The fact that ASD is a neurological disorder and not obvious physically, unlike other disabilities such as Down Syndrome and Cerebral Palsy, people can

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easily mislabel a child with ASD as rowdy and disruptive. The social stigma received by these parents was even worse when it came from immediate family members, such as the child's grandparents and relatives. Instead of trying to understand, accept, and adapt to the child's condition, they blatantly accused the parents of having the child as a punishment for committing past sins. This was expressed frequently by parents on the AM FB wall. The feelings of helplessness and devastation when coping with their child was made worse when they also had to deal with the social stigma. This can be seen in Figure 4.65.

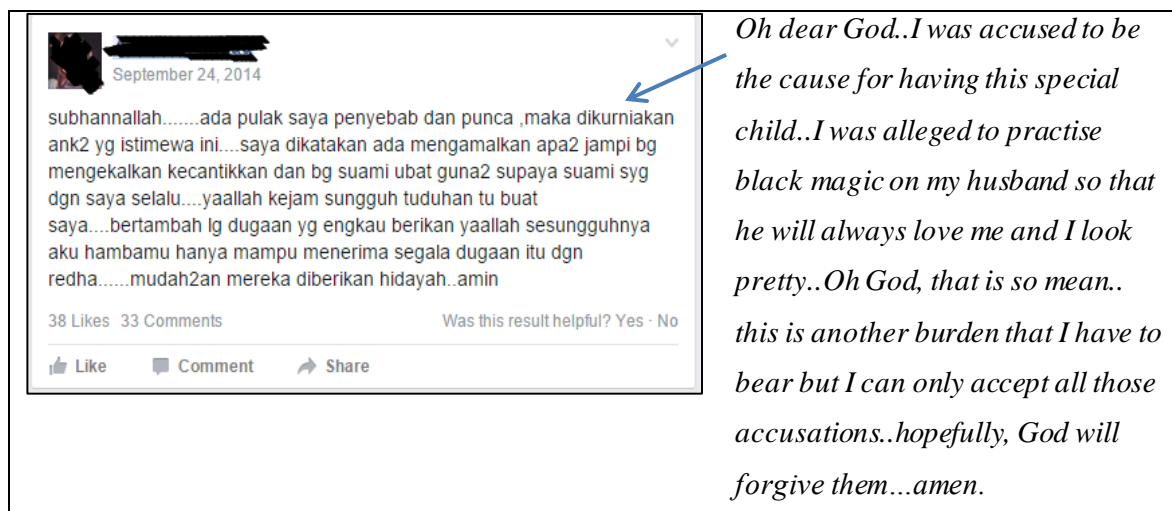


Figure 4.65. Status illustrating discourse of social stigma that parent received.

This social stigma caused discursive struggle among these parents as their efforts of creating awareness by explaining the conditions of their child to immediate family members and the general public often failed. The social stigma from the general public was usually received by these parents when they took their child to the public places such as shopping malls and hospitals. The stigma came in the form of verbal comments or gazes. These actions frequently caused more harm as the comments and gazes were offensive to the parents as it appeared to indicate their inability to parent their child. Exposing their child to outside world was to help their child adapt to their surroundings and create awareness in others. Unfortunately, the response the parents received were often demotivating and disheartening. To deal with this, parents responded differently. Some ignored the social



stigma when going out to public places while others remained with their child indoors and did not expose him/her to the outside world.

### *Self-help vs helping others*

The purpose of this AM FB support group was for parents of a child with ASD to seek emotional, social and informational support. It could be deduced that parents who joined the group expected to gain some form of help from others that would assist with their own challenges associated with bringing up their child. This expectation went beyond self-help as it was also expected by other members that the parents would extend support and engage in helping others. Although it might seem that there was a mutual understanding between the members that help and support would be exchanged, some parents offered support more than others. This was apparent especially from the parents who had been in the group for a longer period as they were regarded as being experienced and knowledgeable. This created a discursive struggle among these parents as they were torn between helping themselves and helping others. Although this was not shown on the AM FB wall, it emerged as a theme through the interview with these parents. Figure 4.66 shows a status in which a parent encouraged members to help others in the AM FB group.

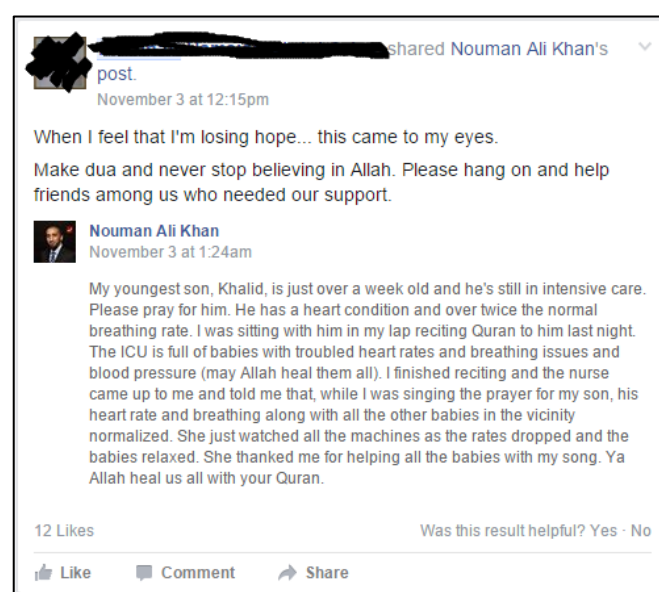


Figure 4.66. Status where parent encourages members to help others in the group.

This parent talked about her experience helping another parent who had approached her through the *pm* seeking support on the AM FB group as she had almost given up all hope of managing her child. It might look like a voluntary extension of assistance, but it could be deduced that this parent had agreed to spend the time assisting another parent personally beyond the virtual world. It could be inferred that this parent faced struggles between helping her own child and helping another parent particularly in the last sentence where she said: “*every hour I would pm her,...as if I’m a nutritionist!*” The interview transcript below illustrates this struggle.

This mother pm me and talked about how her 6 years old son is not eating, only drinking milk. She is stressful as she has to take care of him alone as her husband is working elsewhere. So, I shared with her how I manage my son’s eating habit. After few days, I pm her asking about her child, and she said she wanted to follow my routine but she is too tired because her son is not sleeping well. I motivated her and then every hour I would pm her asking the progress as if I’m a nutritionist!

Although this parent did not clearly share how she dealt with this struggle, it could be deduced that she took it very positively, making it an ‘obligation’ to support others as she did not want other parents to go through the same challenges she did.

#### **4.4.3 Ways parents manage discursive struggles in the AM FB group**

In addition to the approaches discussed earlier, there were other strategies these parents adopted to ease their discursive struggle. This was done particularly when they were posting status related to the future. The two strategies were using (i) politeness and (ii) gentle reminders. Most parents who had experiences with discursive struggles would usually start the status with a polite opening sentence before writing the content of the status on the

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*wall* (Figure 4.67) or reminding the members that only positive responses were expected in the comment thread (Figure 4.68). It seemed that these two strategies were successful in limiting the possibility of discursive struggles on the AM FB *wall* and by private messages.

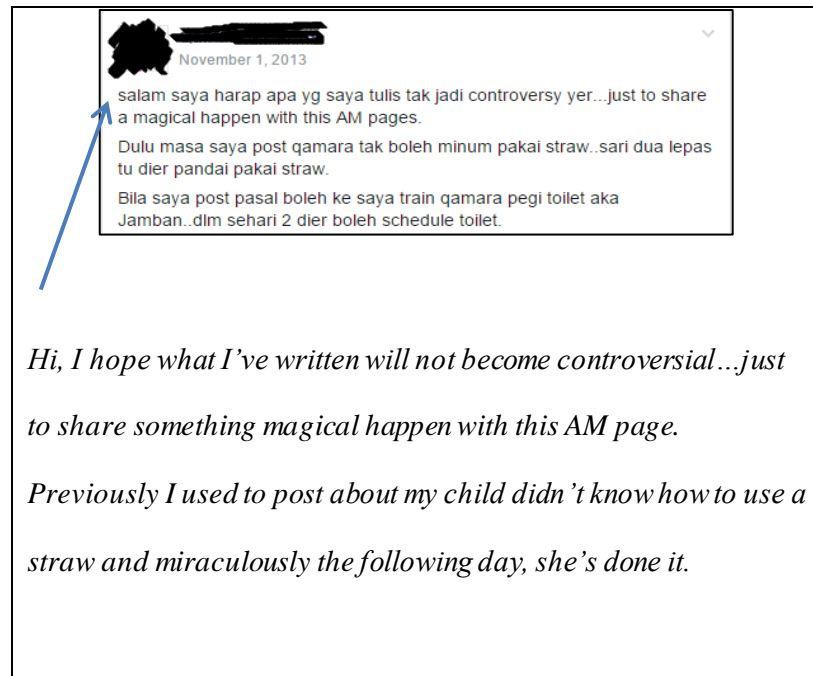


Figure 4.67. Using polite opening sentence before the content

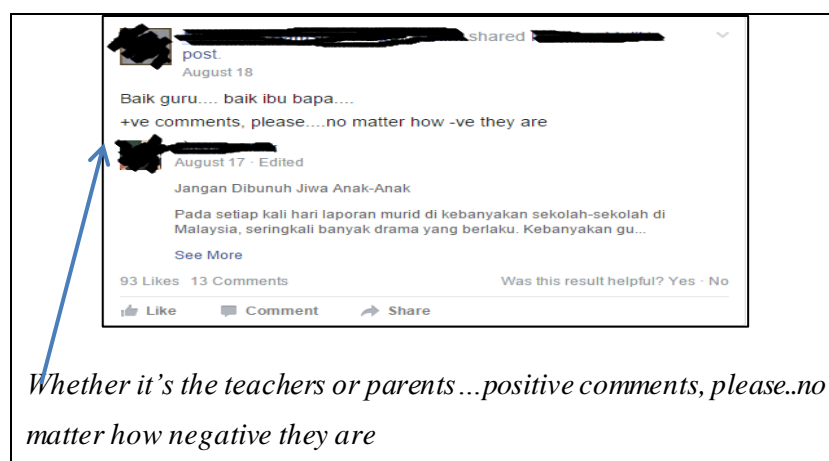


Figure 4.68. Using a gentle reminder that only positive comments are encouraged.

The discursive struggles that the participants experienced were a non-linear process as a negative impact could lead to a positive impact while a positive impact could lead to a

negative impact. However, the way these participants managed the discursive struggles made them wiser in the future especially when posting a status or commenting on another's status. They practised communicative strategies such as using polite opening remarks and gentle reminders so that the posts would not be offensive to other members in the AM FB support group.

### **4.5 Hope for the AM FB support group**

Despite the negative impacts of the Facebook support group, the positive impacts predominated. The negative impacts were viewed mostly as another challenge that the parents had to face but they did not deter their resolve to continue using the AM FB as a platform for seeking support. Compared to raising and caring for a child with ASD, the challenge of managing negative experiences on the AM FB group was seen as 'do-able' or adaptable. Thus, believing in the influence of the AM FB support group as the best platform for parents of a child with ASD, and the participants were hopeful that it was sustainable. In addition, other members had expressed the same hopes and wishes for the group to remain as it benefitted an increasing number of new parents who had joined the group. This was the result of the increasing number of children being diagnosed with ASD and the awareness level of those parents in Malaysia.


#### **4.5.1 Sustainability**

All the twelve participants agreed that the sustainability of the group was related to the sense of belonging and bonding that occurred among members of the group. The sense of belonging and bonding made the members closer although they might not know each other or have met offline. This should be sustained to support the group to function well and ensure all parents benefitted from joining and actively participating in the group. The same views were even shared by other members who openly expressed this hope on the AM FB *wall* as shown in the interview transcript below. Another way to maintain the group's

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sustainability was to hold an offline meeting where parents could meet up and plan social activities as illustrated in Figure 4.69.

“We want the sustainability, we may never meet in the real world but when we read their status, it’s as if we have known them for a long time”. (LW)



Assalamualaikum.

Untuk makluman warga Kulim dan sekitarnya. Kami merancang untuk memulakan Kelas Pengajian Quran dan Ibadah buat anak istimewa atau OKU di Kulim dan mewakili kawasan utara. Kerjasama dengan Yayasan Faqeh- Yayasan Pendidikan Al-Quran bagi Anak Istimewa

Sesiapa berminat membawa anak menyertai komuniti kami ataupun menjadi tenaga pengajar, boleh wasap atau sms [redacted] di nombor 0124009293.

Perlu ditekankan di sini bahawa konsep kelas ini bukan seperti kelas pengajian Quran yang biasa( ibu bapa hanya hantar anak dan akan ada guru yang mengajar ) tetapi ibu bapa sendiri perlu sama-sama hadir dan membimbing anak masing-masing. Komitmen dan sokongan daripada ibu bapa amat-amat diperlukan.

Terima kasih.

Like · Comment · Share

5 Mera Yusof and 24 others like this

*Greetings.*

*For those staying in Kulim and nearby areas, we planned to hold Quran recitation and prayer class for our special children in the northern area with collaboration with Faqeh Foundation- Quran education for children with disabilities.*

*I would like to emphasise that parents need to attend together with their children and guide them. Your commitment and support are strongly encouraged.*

*Thank you.*

Figure 4.69. An example of social activity held offline for the members staying nearby areas.

### 4.5.2 Future undertakings

What the future holds for their child with ASD was another concern that most parents shared. Through the AM FB support group, they wished that parents of older children with ASD would shed some light on the paths available for their children when they grew up. How these parents managed the transition from childhood to the teenage years and adulthood was what these new parents hoped to learn as illustrated in Figure 4.70 below.

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

The sharing of experiences would provide assurance that their child had a future with the right guidance and assistance not just from the parents but also from others including teachers, schools and educational departments, medical professionals, and also the public in general. This hope was shared by all the twelve participants during the interviews and by other parents on the AM FB wall.

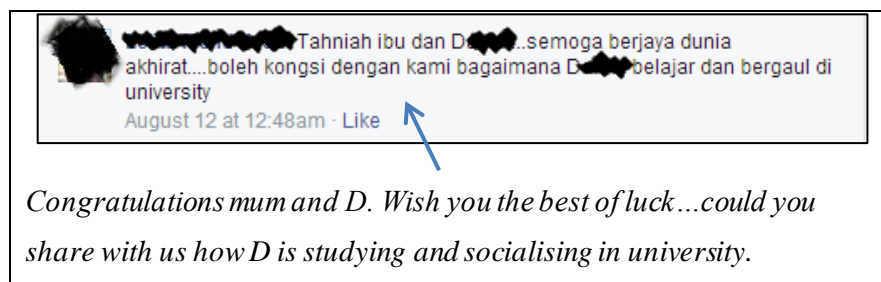


Figure 4.70. Seeking experiences of teenager with ASD for future reference.

### 4.6 Conclusion

This chapter presented the detailed results and findings from the three data sources analysed in this study. The analysis process was performed using Microsoft Excel (participant observational data) and NVivo software (archived Facebook data and semi-structured interviews) using frequency count, and thematic, grounded theory analysis and discourse analysis, as the underpinning theories. The results indicated that Autisme Malaysia Facebook support group had provided these participants with the appropriate social supports that they sought to obtain from an online platform. The significance of the experiences shared and gained from communicating on Autisme Malaysia Facebook group was highly valued by the participants and they hoped for the sustainability of the group in future.

Based on the results obtained from the data analysis, the following chapter offers an analytic discussion of the findings. It provides a comprehensive discussion of the data analysis results and how these findings were related to the literature reviewed in Chapter 2. The findings highlighted congruent and supported the theories reviewed as well as incongruent and contrary theories. The findings were discussed in terms of the research objectives and how these findings had answered the research questions.

## CHAPTER 5: DISCUSSION

### 5.0 Introduction

This chapter examines if the research objectives of this study were addressed and achieved. The findings in Chapter 4 were constructed based on the two data sets with the qualitative part being highlighted as it provided a more in-depth understanding of the participants' experience in using the AM FB support group. The grounded theory analysis produced three major categories that were intertwined. These led to positive and negative impacts on the participants. Discussions in this chapter, on the other hand, are constructed based on the research objectives and research questions. The analysed data was revisited and then compared with the theories and concepts reviewed in the relevant literature. Some of the findings were strongly supported by the literature; by contrast, contradicted those arguments made by other researchers.

### 5.1 Research Objective 1: To explore the experiences of parents of a child with ASD in Malaysia participating in Facebook support group called Autisme Malaysia (AM)

5.1.1 Research Question: a) What constitutes parents' online engagement in Autisme Malaysia?

#### *Online engagement*

Online engagement for the participants in this study in the context of the Autisme Malaysia Facebook group extended beyond a merely seating in front of a computer, logging into Facebook and communicating with other members in the group. It involved the self-motivation to communicate online, which was a motivating factor that influenced other

members to communicate actively on the *wall*, the sharing of experiences and expression of feelings, and utilising the communication features offered by Facebook (synchronous and asynchronous).

The findings from participant observation provided a general overview of what activities were conducted on the AM FB *wall* which further investigation of the archived Facebook data enhanced and provided an in-depth understanding of these activities. The frequency of activities conducted by the participants was an indication of their engagement with the AM FB support group. It can be claimed that the more frequent the participants conduct activities on the FB *wall*, the higher their engagement with the online group. By contrast, fewer activities conducted on the *wall* indicated less engagement with the group.

Although there was no intention to compare the engagement of the genders, there was more engagement in the AM FB support group by mothers of a child with ASD. In fact, the participants in this study was composed of more mothers than fathers. Perhaps communicating with the same gender on an online platform was a motivating factor for mothers to engage more frequently with the AM FB group. This is consistent with previous findings (Gaber & Hundertmark-Mayser, 2005; Grande et al., 2006; Waldmann, Pritzke, Raspe, & Katalinic, 2007) specifying that self-help group participation is higher among women and disputes the claim that women feel less comfortable participating in online support groups even when they had equal access to the group (Royal, 2005). This finding is consistent with another study in which women who were not employed full-time were highly engaged in internet activities including searching for health information (Rice, 2006). One solid reason to explain the higher level of involvement of mothers in the AM FB support group is that “females have great capabilities to balance offline and online connections, and are also more skilled in social bonding online and thus explains why they use social networking sites more frequently and interact more socially than males” (Brandtzæg, 2012, p. 483). The problems shared by these mothers on the AM FB *wall* went



beyond the challenges of managing their child as there were instances where issues with their spouses were shared on the *wall*, which could also explain their higher level of engagement. Consequently, it can be claimed that responsibility of managing and parenting their child largely fell on the mothers rather than the fathers. This is supported by a study conducted in Turkey in which greater responsibility for caring for a child with ASD was endured by the wives, and this alleviated their interactions and relationship with their husbands (Aylaz, Yılmaz, & Polat, 2012). However, this does not mean that all fathers in the online support group did not take part in managing and parenting their child, as work commitments meant that they preferred that their spouse participated in the AM FB support group.

The frequency with which one updated their status or commented on others' status was an indicator of online engagement for the participants in this study. The very act of participation in social media makes content widely available to many interested parties, including the 'public' (boyd & Marwick, 2011) and users have to ensure that their postings are meant for a certain group of people ('Friends') or for all ('Public'). Facebook does not only allow its users to use language to update their status but offer other features such as emoticons to express moods and feelings. Most social networking sites encourage their users to conduct a variety of activities (social connections, shared identities, photographs, content, social investigation, social networking surfing and status updates) and express gratifications (Joinson, 2008). This is what is offered by Facebook. These practices have been proven to assist with connectedness, not just information exchanges (Nardi, Whittaker, & Bradner, 2000) and fulfil the role of phatic communication. Social media technology has the ability to fundamentally change how its users engage with each other. The features in Facebook include tools to facilitate engagement (Benkler, 2006; Carlisle & Patton, 2013). The features such as Like, Comment and Share are the catalyst of this engagement for users and logically, the more time spent on Facebook can reflect a user's level of engagement. On the

other hand, one study found that a large amount of time spent on Facebook does not reflect a high level of engagement on the engagement survey scale (Junco, 2012). This, however, was not evident in the findings of this study in which members of the AM FB group connected with each other after more information was shared on the AM FB *wall*. This connection and engagement with group members were further developed when members choose to communicate synchronously through private messages (*pm*).

Based on the findings, it can be asserted that building a network was a result of the online engagement of the participants in the AM FB group. Social networking updates may have been personal (Naaman, Boase, & Lai, 2010); concerning an activity, a location, or a mood with the intention of specifically building a network in an online social support group. Building social networks both offline and online has been proven to provide emotional support, information resources, and relationship with other people (Ellison, Steinfield, & Lampe, 2006). This claim justifies the findings in this study as members start with building an online networking through the AM FB group and then extending it offline by holding regular meetings with those in the same geographical location. The networks and relationships were strengthened through various activities by the members of the AM FB group such as excursions, courses, and festival celebrations. This networking made AM FB the best platform for parents of a child with ASD as cited by the participants in this study. This is the avenue where support is exchanged and relationships generated with the ultimate aim of helping both the children and the parents. These relationships which were the result of the Facebook network appeared to be easier as members in the AM FB group consisted mainly of one ethnicity (Malay). Although AM FB is an open group which encourages parents of different ethnicities, and there is evidence that Chinese and Indian parents have joined, the group is dominated by Malay parents. Having different ethnic groups within a social support group may not affect participation as found in one study (Michalec, Van Willigen, Wilson, Schreier, & Williams, 2004) as there was no difference found in the

overall participation in support group between Black and White breast cancer patients. Thus, ethnicities in a support group should not affect the engagement of group members, as confirmed by the AM FB group.

### ***Motivation as a catalyst for online engagement***

As described earlier, motivation is one of the categories that constituted online engagement for the participants in this study. The motivation to engage with the Facebook group and eventually motivate other members to actively communicate was an indication of the participants' engagement with the AM FB group. Findings of the motivation to join the AM FB support group were congruent with the socially-oriented motives suggested by Kevin (2013) in which parents participated due to "(i) *interpersonal motives*, or the goal/desire to use the medium to develop, enhance, or maintain relationships" (p. 45). As highlighted in Chapter 4, the parents were interpersonally motivated to join the AM FB group due to several reasons including dissatisfaction over the lack of local online support groups, infrequent face-to-face support groups for their child and none for parents provided by the local government hospitals, and challenges in managing their child with ASD. Thus, being a member of the AM FB group was the only option for these parents to seek help and support by sharing their experiences. This effort made by the parents is called 'self-help'. According to McGill et al. (2006), "A 'self-help' focus on family training, advocacy and family-to-family support might achieve more" (McGill et al., 2006, p. 651). This is where a support group can bridge the 'self-help' gaps. These findings are consistent with earlier studies that claimed that the reasons parents join support groups was to seek new information, share experiences with others and get emotional support (Huws et al., 2001; Solomon et al., 2001). Sharing was greater when it was done with people who were not close to them as seen in an online setting. Research also found that individuals were more likely to disclose sensitive information to network with weaker ties (more distant friends rather than family members or close friends) such as those in online social support

networks/communities due to the lowered interpersonal risk and the advantage of obtaining more diverse information about a problem which consequently enhanced support satisfaction for those individuals (Wright, Banas, et al., 2010; Wright & Miller, 2010).

Weaker ties tend to be more heterogeneous than stronger ties, which clarified the intensity of information being disclosed and shared by parents in the AM FB support group.

The reasons why parents in the AM FB group joined the support group were similar to those of participants in a study on the use of e-mails among parents of children with disabilities in the US. These reasons include “(a) expressive story-telling, (b) seeking and giving advice, (c) seeking or offering validation or encouragement, (d) seeking or providing information, (e) seeking or suggesting resources, and (f) sharing celebrations and telling success stories for hope” (Aitken, 2008, p. 3). The reasons for joining an online support group were largely influenced by the parents’ own initiative to find alternative sources for learning about their child’s differences. It is driven mostly by their inquisitive nature as a parent when they realised that their child is different from their other siblings or from other people’s children. In contrast to the online support group, parents are more likely to join a face-to-face support group after receiving a referral from clinicians or if their children have self-injurious behaviour, sleep problems or severe language deficits (Mandell & Salzer, 2007). The parents in this study, however, were motivated to join even before getting their child a proper diagnosis. In some cases, they joined when they felt there was something different about their child. This encouraged the participants to find an online support group to learn more about ASD and this constituted their engagement with the group.

The findings in this study showed that most of the participants started off as observers or lurkers (a term commonly used to describe users who are passive members in an online community joining social media) (Preece, 2000). They could also be characterised as ambivalent socialisers who typically preferred to read rather than actively contribute (Ploderer et al., 2015). These parents in the AM FB group who had recently joined, preferred

to be silent readers reading other members status updates and comments and put into practice any information deemed to be useful and helpful for their child. A similar claim was made that *lurkers* learn vicariously by reading the experiences of other participants in an online group (Arnold & Paulus, 2010). The reason these parents prefer to be silent readers is because they are unsure how to help (Chesler & Barbarin, 1984) or they feel their efforts would not make a difference (Brickman et al., 1982) due to their inexperience and lack of knowledge of parenting a child with ASD. However, this feeling is slowly diminished as these parents realised the effect that active communication on the *wall* had on them. It has been claimed that the success of a social network site depends highly on the quality of content the users or members share (Benevenuto et al., 2009). Hence, when members of the AM FB support group become 'friends' with others and have been *lurkers* for some time, they feel motivated to participate actively in the communication that took place on the AM FB *wall*.

Although there are debates whether the online environment is more valuable when it turns *lurkers* into posters (Edelmann, 2013), in the context of the AM FB group, it proves to be valuable. The shift from *lurkers* to active communicators or posters was due to the desire of these parents to communicate their needs. A similar view of communicating with others using Facebook versus face-to-face interactions is that the need to communicate likely stems from other needs such as convenience and other factors that are unique to social networking sites (such as metacommunication, or commenting on another individual's *wall* posts or status) (Kevin et al., 2013). This finding is also consistent with another study in which newcomers who see their friends contributing to the online group are driven to share more content themselves, while those who were initially active in contributing, receiving feedback and having a wide 'friends' list would increase their sharing (Burke, Marlow, & Lento, 2009). This indicates that 'friends' do have an impact on the behaviour of users of social networks particularly Facebook. This is also consistent with a study by Barker et al. (2010)

that discovered a relationship between a larger social networks and lower levels of anxiety and depressive symptoms among mothers of adolescents and adults with ASD. The same theory was proven as messages directly influenced 61 million Facebook users during the 2010 US congressional elections in terms of political self-expression, information seeking and real-world voting behaviour (Bond et al., 2012). Messages have a great impact on not just the users who received them but also the users' friends, and friends of friends, which indicates that strong ties are crucial for spreading both online and real-world behaviour in human social networks. Ray, Kim, & Morris (2014) also suggested that individuals who experience a strong connection with an online community or group may have a sense of community engagement, which drives them to contribute knowledge and promote the community or group via word of mouth, and eventually motivate others to join in. These individuals could be said to possess "*social integrative motives*, which involve using the medium in an attempt to find information about relational partners and helping individuals feel connected with others" (Kevin et al., 2013, p. 45) when they were able to motivate others to join the AM FB support group. This is the most important factor ensuring the sustainability of the AM FB support group so that it would not become inactive and *dead* as keeping members committed, attracting new members, and encouraging contributions are ongoing challenges that lead to the success of many online communities (Kraut & Resnick, 2012). Hence, this shift of roles from *lurker* to active communicator in the AM FB group was an indication of how motivation drives participants to be highly engaged online.

### ***Trust contributes to online engagement***

Another aspect of why the participants engaged online is the trust that they gained when communicating in the AM FB group. The findings suggested that sharing experiences on the AM FB *wall* was a way for these parents to communicate, build networks and socialising with other members in the group. As these parents tended to feel lonely due to the demand of parenting and managing their child with ASD, and facing other challenges

that made matters worse, they believed that it was only through the AM FB group that they could have ‘friends’ to talk to. This indicates the trust that these parents had in other members of the Facebook group. Their high level of trust in this Facebook group can be seen as they shared matters that others may deem very personal related to their lives; children, and spouses. They felt a sense of belonging to the group and even regarded the group as their extended family. This sense of belonging could be driven by the type and quality of support offered, the person providing the assistance, and contextual issues, which all played an important role in determining whether parents perceived support as beneficial (Ekas et al., 2010). This contradicted the claim that there is a heavy social cost associated with using social networking sites, which can contribute to decreased social involvement, less face-to-face interaction, and increased loneliness or isolation (Morris, 2010; Turkle, 2011). Consequently, the users of such sites differ from person to person, and dissimilar patterns of usage could have different social implications (Brandtzæg & Heim, 2011). However, in this study of the AM FB group, all participants agreed that the platform helped them become socially involved with other members. Although most of the interactions occurred online rather than face-to-face, they felt as if they have known each other for some time and that they did not feel lonely anymore. Logging into the AM FB group every day increased their social involvement as they had ‘friends’ to talk to. This indirectly influenced other members to do the same by communicating and sharing things regularly on the AM FB *wall*. This is explained by the view that technology has been proven to provide individuals with avenues to build a network of connections, to be influenced and to influence that network exponentially (Bond et al., 2012).

Another robust factor for these parents to go online was to gather information that could influence their decision-making regarding treatment for ASD (Balka, Krueger, Holmes, & Stephen, 2010). However, in the context of the AM FB group, instead of new information, parents sought information due to their lack of knowledge and available

resources from the government. Decisions regarding treatment, or therapies in the context of this study, were generally influenced by other parents' experiences. When parents shared workable, tried-and-tested therapies that yielded positive outcomes on the AM FB wall, these were influential factors that encouraged other members to try these therapies on their own child. Due to the overwhelming number of therapies, which are medically or alternatively-driven (such as homeopathic treatments and supplements), available on the internet, parents in the AM FB group were faced with big decisions when choosing the right treatment for their own child. Thus, when other parents share their tried-and-tested therapies, they become more confident when choosing the same therapies for their child. The influence of this networking was greater than the experts' advice regarding treatment. This shows the profound trust these parents had that encouraged them to be highly engaged online.

### ***Shared similar challenges establishes online engagement***

The findings in this study also suggested that the participants sharing similar challenges on the AM FB group established and strengthen their online engagement with other members of the group. As most of the parents of a child with ASD in Malaysia go through almost similar challenges and experiences, despite the differences of the child's condition due to the wide spectrum of ASD, sharing them in the group is the only or perhaps the best option so far. The findings revealed multiple challenges faced by these parents including medical-related issues, financial, information scarcity, and parenting skills.

The participants highlight the medical-related issues such as confusions over the procedure for getting a diagnosis for the child, doctors who lack knowledge about ASD, a long waiting-list for diagnosis, and inaccessibility to ASD experts in the surrounding area. Parents in the developed countries such as the United States have faced similar challenges in the last ten years. Families of children with autism also confront difficulties with health care needs such as health insurance, public support, specialised providers (Krauss, Wells, Guley, & Anderson, 2001), information related to where and how to get services and fees (Bailey,



Skinner, Hatton, & Roberts, 2000; Coonrod & Stone, 2004; Whitman, 2004), obtaining specialist referrals, and finding appropriately-trained specialists (Krauss, Gulley, Sciegaj, & Wells, 2003). Similar findings were reported by Mroz and Letts (2008) as families with children who qualify for special education services faced complex challenges, which included difficulties in diagnosis and variations on the kinds of services and supports received. Due to the partnership and communication problems that parents have to endure with professionals, they felt that more parent training and emotional supports are needed and they value regular, reliable, and continuous support (McGill et al., 2006). In addition, parents in the United States were indecisive when choosing between the vast options of treatment suitable to meet their children's needs (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Mandell & Novak, 2005). Thus, it is not surprising that the same challenges are faced by parents in a developing country like Malaysia. As healthcare providers become more advanced in the United States, the same may occur in Malaysia but it may take some time. However, at present, the only platform that these parents could depend on is the AM FB support group. This is an avenue for them to get relevant and reliable information. It was highlighted in the introduction chapter that past research examined Caucasian parents in Western countries and even if it involves other ethnicities, the setting was still in a Western country. One example is a study on African-American parents of children with autism in the United States claimed that these children received a diagnosis at a later age, when they were school-aged (Liptak et al., 2008; Mandell, Listerud, Levy, & Pinto-Martin, 2002). This is consistent with the findings of this study in which most children in Malaysia obtained diagnosis at the age of five or later. However, as more concerned parents join the AM FB support group while their child is younger than two, they will benefit from the information other experienced parents share, and they can express their anxiety over their child's differences.

Financial constraints are one of the challenges commonly shared by the participants on the AM FB *wall* and this leads to a higher level of engagement with the group members. Financial constraints could be related to the late diagnosis of their child as they have to wait for the longer administration procedure required by the government hospitals. If they were to opt for a private hospital for earlier diagnosis, it would incur higher costs for these parents. Additionally, sending their child to private therapy centres also demanded a higher expense in comparison to the infrequent and cheaper options provided by the government. The cost may be affordable now in developed countries compared to the developing countries like Malaysia, but back in 2002, parents of a child with disabilities in a developed country like the United States faced a similar challenge associated with higher cost for diagnostic and treatment services (Flanders, Engelhart, Pandina, & McCracken, 2007). Furthermore, financial constraints may be due to the fact that fifty percent of the participants were not working (housewives) and did not have the means of earning income to help with the cost of managing their child. Thus, it is not surprising to discover such high costs for parents in Malaysia choosing to engage private services.

Another similar challenge frequently shared by the participants in the AM FB group was parenting skills, which is perhaps the most common concerns for parents of a child with disability. The challenges faced by Malaysian' parents as illustrated in Chapter 4 are consistent with those of parents in Turkey and include difficult family relationships, social and economic challenges, and coping with the educational and problematic behaviour of the children (Aylaz et al., 2012). It seems that the challenging behaviour of a child with ASD is the cause of other problems faced by parents in the AM FB group. It appears to have a snowball effect as the child's behavioural issues lead to parental stress, as not only do they have to deal with their child with ASD, but they also must deal with any other typically developing children that they have. The parents felt that due to the greater attention and focus given to the child with ASD, they might neglect their other children. Findings in this

study of the AM FB group were also consistent with other studies in which parents struggled with ways to cope with psychological (Kogan et al., 2008; Preece & Jordan, 2007) and financial difficulties, education, lifestyle (socio-cultural and recreational activities), relationship in the family and society, status of the child's disability, and uncertainty about the child's future (Doğanmez, Bayhan, & Artan, 2000). Family support services were highlighted as being scarce for parents raising children with autism in the United States back in 2005-2006 (Kogan et al., 2008). As discussed earlier, these challenges were reported by the parents of a child with ASD in developed countries more than ten years ago and it is not surprising that parents in the developing country such as Malaysia face them now.

The findings in this study also revealed that the parents struggled with various education-related issues including being rejected by mainstream schools (even though the national education policy stated that all students with disabilities have the right to go to whatever school the parents choose), untrained teachers, and social stigma on the part of the school administrator, teachers and students. These commonly shared challenges were expressed numerous times by the participants on the AM FB wall and they drove them to engage even more with the Facebook group. The parents felt that they should be 'included' in school matters. It was highlighted that parents should be provided with clear messages regarding the schools' goals, parents' rights and responsibilities should be clarified, parents should be included in planning and decision making, and parents' knowledge as caregivers should be respected and their hopes for their child should also be supported (Nachshen & Minnes, 2005). Furthermore, it is crucial that the parents be made aware of the learning that takes place in the classroom so that it can be further practised and emphasised at home by the parents. The parents' knowledge is vital for teachers and the school as their child spend most of their time at home with their parents, especially those with non-working mothers, and the parents have better knowledge of their child's behaviour and attitude. The collaboration between the parents and teachers could ensure an appropriate education

program such as IEP (Individualised Education Program) is designed to suit the needs of a child with ASD. This is further justified by the claim that a parent's role together with a manageable and efficient service system (refers to the school, administrator and teachers) is crucial to ensuring that parents could manage their child's behaviour (Samadi, McConkey, & Kelly, 2012). This can only be accomplished when parents are constructively and actively engaged with the service system through their empowerment and family-centred models of service delivery (Brookman-Frazee, 2004; Nachshen & Minnes, 2005). These models increase parental satisfaction with the delivery of services (Trivette et al., 1996), have better results in child interventions (Brookman-Frazee, 2004) and increase parent self-efficacy (Brookman-Frazee, 2004; Dunst et al., 2007). Mandell and Salzer (2007) also shared similar view that "family members who have 'been there' and shared similar experiences can support one another, provide critical information about where and how to obtain services, and, in some cases, can come together to advocate for needed resources and supports" (p. 119). Therefore, parents of a child with ASD in Malaysia should become empowered to ensure that their child has the best education possible and it can only be successful with the help from those who work at school (administrators, teachers, therapists).

5.1.2 Research question: b) What kind of support is exchanged in Autisme Malaysia Facebook support group?

### ***Social support***

The findings of this study on the AM FB group illustrated that the parents found informal social support to be very useful for them and their child with ASD. Informal social support is found to "reduce levels of parent stress proliferation, the tendency of stressors to engender additional stressors in other life domains, and parent depression" (Benson, 2006, p. 685). McTavish et al (1995) also found that cancer patients who used the internet cancer support group as a source of support and health information were reported to be less socially

isolated, and have increased personal empowerment and self-esteem. This claim can also be applied to this study as it means that parents who have such support are able to minimise other stressors related to having a child with ASD. This is congruent with a study (Hastings & Beck, 2004) that the potential value of parent-led support networks was that they could alleviate parental stress for parents of a child with disabilities. This is evident in this study in which the parents who received informal social support through the AM FB group had less related stress and more positive outcomes. Later, they were able to provide support in their online and offline communities. The prompt reply from other members is one of the benefits of computer-mediated support groups and using Facebook as a platform allows for valuable support to be provided because it is immediate and personalised (Mustafa et al., 2015). This finding also dismisses the claim that the number of hours spent using Facebook was positively correlated with depression (Kevin et al., 2013) as the parents in this study indicated that they logged in and communicated on the AM FB *wall* almost every day. This could be explained by the motives for logging in and the activities that these parents conducted in the AM FB support group as Kevin et al (2013) highlighted that individuals who used Facebook simply for passing time instead of interpersonal communication may be more depressed. Hence, the parents in this study can be said to have less depression as they spent most of their time in interpersonal communication on Facebook.

### ***Informational support***

The findings related to informational support as one of the supports that the parents sought online in this study were due to the internet being a reliable source of information for most support groups. This is substantiated by a study on the parents of a child with Cornelia de Lange syndrome (CdLS) that “internet support groups have been helpful in finding medical information and support, with the most commonly impacted areas of their child's care including day-to-day management, diet, therapy interventions, and healthcare providers” (Cacioppo, Conway, Mehta, Krantz, & Noon, 2016, p. 229). It is also consistent with

another study of women with breast cancer who found online support groups provided informational support, which then influenced their health-related decisions, knowledge about their next action, or to seek social support (Balka et al., 2010). However, within that study by Balka et al (2010), the internet was one of the most consulted sources for information about the women's illness but it was not the most trusted or most utilised source of information. Similar findings were reported by cancer patients as only 7% - 10% seek information or support online as they were doubtful of the reliability of the medical information that they found (Diefenbach et al., 2009; Mills & Davidson, 2002; Raupach & Hiller, 2002). This contradicts to the findings in this study of the AM FB group whereby the information shared (the parents' own experience or related links of ASD) was the information most trusted by the members and at times it surpassed the trust they had in the information given by therapists. This could be due to the frequent mismatch between the needs of parents of a child with disabilities and the services provided by experts such as the therapists (Krauss et al., 2001). This is similar to a study in which women valued opportunities for practical and experiential knowledge gained through peer contact in online support groups rather than face-to-face support groups (Barnett & Hwang, 2006). A study by Eakin and Strycker (2001) also found many cancer patients felt more comfortable obtaining information over the internet than using traditional cancer support services. The findings from these two studies validate the finding of this study on the AM FB support group.

The findings in this study also suggest that the participants viewed other parents of a child with ASD as their biggest supporter, not only for informational purposes but for other types of support as well. However, this is inconsistent with the finding of a study of parents of a child with ASD in the UK in which other parents' support was viewed as less helpful (Bromley et al., 2004). Perhaps the difference can be explained by the scarcity of reliable information from both governmental and non-governmental organisations in Malaysia that made the parents' informational support highly valuable in the Facebook support group.

Hence, they greatly valued the support provided by other parents because they could not get it elsewhere.

### *Emotional support*

The parents of a child with ASD in Malaysia faced numerous challenges in this study and these findings are congruent with the notion that coping with these challenges have led to higher levels of stress (Benson, 2006), lower overall well-being (Ekas, Whitman, & Shivers, 2009) and social and emotional burden (Webster, Majnemer, Platt, & Shevell, 2008). This is further supported by a study (Lam et al., 2010, p. 373) that highlighted “the fact parents with a child with ASD experience more emotional stress than the parents of developmentally normal children, mutual support groups or self-help groups would be helpful in supporting them and enhancing their resilience”. In fact, the child’s challenging behaviours and low levels of family support were reported to be “the significant factor which led to maternal distress compared to other developmental delays” (Bromley et al., 2004; Estes et al., 2009). This was further supported by Lyons et al (2010) who stated that the severity of ASD in children is a strong and consistent predictor of the parents’ general stress. The findings in this study were also consistent with a study by Bromley *et al* (2004, p. 420) that found that “mothers supporting children with ASD in The United States found that high levels of psychological distress was particularly associated with low levels of support from within their family and bringing up a child with higher levels of challenging behaviour”. It is interesting to note that the findings of this study involving parents in Malaysia were similar to the findings of a study in the United States that also confirmed that the lack of support from immediate family members lead to greater emotional stress. The high demands of parenting and managing their child may overwhelm parents’ coping resources, resulting in greater stress and concern. Coping with the challenges managing their child was another factor contributing to the emotional stress of the parents in the AM FB group. The emotional stress was greater for younger mothers than it was for older mothers

(Barker et al., 2011) and this was proven through the archived Facebook data on the AM FB *wall* where young mothers who just joined the group posted more emotional posts. This explains the pertinent findings of this study in which emotional support was the second most common social support mechanism being exchanged on the AM FB *wall*. It seems that expressing emotional stress on the Facebook *wall* helped them alleviate stress by gaining support from other members and this was achieved through the active engagement in the AM FB group.

The social stigma from immediate family members and society highlighted in Chapter 4 was the second most common contributing factor of emotional stress among the parents of a child with ASD in the AM FB group. This is substantiated by the claim that socially inappropriate and disruptive behaviour displayed by their children were highly likely to entice external disapproval and negative perceptions from others (from family members and strangers) which lead to high parenting stress (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014). There was also a claim that patients who lived alone were less likely to receive social support from a spouse or family members; thus, they were more likely to seek emotional support from others (Osborne et al., 2005). Due to the external disapproval and negative perceptions from others, the parents in this study found it challenging to expose their child to the outside surroundings as the child's behaviour attracted the gaze and hurtful remarks. The parents were not alone in facing social stigma as other family members such as the siblings of the child with ASD, were affected too. There is a clear indication that families need support as they become isolated from the community, sometimes "affecting the social life of siblings which leads to social exclusion for the family as well as for the child with a disability" (Brown, Geider, Primrose, & Jokinen, 2011, p. 916). Thus, emotional support is crucial for these parents so that they can deal with social stigma and social exclusion from others.



Social support is a pivotal factor that reduces the psychological effects of coping with a child with ASD. Support is provided by friends and families (Bishop et al., 2007; Rini, Manne, DuHamel, Austin, & Ostroff, 2008). The findings in this study proved that support from other parents in the AM FB group, which they considered to be extended family members, reduced their emotional stress. This is parallel to a study on Caucasian mothers (Ekas et al., 2010) that found that partners, spouses, and friends had a direct impact on some aspects of a mother's well-being. Family support functions indirectly by helping mothers become or remain optimistic when coping with the challenges of raising a child with ASD. The challenges in managing a child with ASD have a greater long-term effect on parents in comparison to parents of a child with other disorders, as the child moves from childhood to early adulthood (Montes & Halternam, 2007; Totsika, Hastings, Emerson, Lancasters, & Berridge, 2011). A similar finding was reported among European-American mothers who experienced an increase in stress and negative impact as their children transitioned from late childhood into adolescence (Putnick et al., 2010). This explained the finding in this study as the parents hope to learn more of their child's future undertakings, particularly the transition from childhood to teenage years and to adulthood, when they join the AM FB support group.

Informational and emotional supports are commonly reported from the findings in other studies investigating online support groups, such as those for Huntington's disease (Coulson et al., 2007), and HIV/AIDS (Coursaris & Liu, 2009). Findings on the AM FB group studies showed that informational support was the most sought followed by emotional support. This order was reversed in studies on online support groups for postpartum depression patients (Evans et al., 2012) and cancer patients (Love et al., 2012). This indicates that the parents of a child with ASD in Malaysia were more in need of informational support than they were of emotional support. Regarding the idea that the ethnicity or cultural background of the parents in using online support groups can influence the results, the recent study on the AM FB group shows that Malay parents used the

Facebook support group platform to seek out and provide informal support. These findings challenge the findings that women of colour are less likely than White women to seek help from others (Johnson, 1997) because the former group has a greater dependence on family, friends, and neighbours for support (Carveth & Gottlieb, 1979). Hence, this is not the case among the parents in the AM FB support group as they depend more on other members rather than their family, friends and neighbours for support.

### ***Religious support***

The findings in this study show a strong religious support being exchanged among the parents as a way to support each other. Kim *et al.* (2011) claimed that individuals who have lower levels of religious coping strategies are more likely to receive emotional support from others in an online cancer support group. Islam as a religious faith for almost 90% of the members in the AM FB group underpins the support which reminded the parents that their child, regardless of typically developing or with ASD, are a blessing from God. Parents blessed with a child with ASD or any other disabilities are given greater rewards in the afterlife despite the challenges they face in this world. Strong faith in the religion is a way of life which provides such spiritual strength to these parents that they are able to spread it to other parents in the Facebook support group that assist the parents in dealing with everyday challenges managing the child with ASD. This can be supported by the claim that gaining spiritual strength has been proven as a factor which contributes to a family's becoming stronger in spite of dealing with adversity such as those who have a child with ASD (Bayat, 2007). This explains the vital role of religious support for these parents in the AM FB group.

The parents' faith in Islam is further supported by the scriptures in the Holy book, the Quran, which parents frequently share as a reminder that the child is indeed a blessing and also a trial for them. In fact, the child who has disabilities is considered as a greater trial for their parents but there is a reward for those who are able to endure this challenge. Thus, to obtain this reward, the parents have to accept their child with ASD with open hearts and

this is frequently communicated on the AM FB *wall*. This reward is illustrated in the lines quoted below in the Quran.

(At-Taghabun -The Manifestation of Losses, 64:15) **انما اموالكم واولادكم فتنة والله عنده اجر عظيم**

*“Your wealth and your children are but a trial, and Allah has with Him a great reward”.*

(Al-Anfaal – Voluntary Gifts, 8:28) **واعلموا انما اموالكم واولادكم فتنة وان الله عنده اجر عظيم**

*“And know that your wealth and your children are a temptation and that Allah is He with whom there is a mighty reward”.*

5.1.3 Research question: c) In what way do the linguistic and paralinguistic features in Facebook allow parents to exchange this support?

Like any other online support groups that use various platforms (e-mails, bulletin boards, chat room), Facebook perhaps offers more by providing both the communicative features, synchronous and asynchronous communication for its users. Paralinguistic features, such as feelings intensifier, emoticons and ‘Like’ button, can be found in Facebook in order to substitute the non-verbal communicative features which commonly occur in a face-to-face communication. Findings from the participants’ observation on the activities conducted by the participants on the AM FB group shows that they fully utilise the features offered by Facebook. The *wall* has become a platform to share everything related to their child, and ASD-related matters, both positive and negative. The parents also pose questions openly on the *wall* to gain other opinions and to express their feelings and problems either personally (parenting skills) or professionally (medical-related, education-related). All these appear on the members’ newsfeed which allow them to silently read as inactive participants or respond to the statuses as active participants. The newsfeed and *wall* features in Facebook are distinctively positioned to facilitate online engagement and act as mechanisms to support the individual’s voice (Carlisle & Patton, 2013). This can be seen from the frequency of

postings being made by the participants in the previous observational sheet. Almost all participants contribute to the postings every week within the period of three months of observation. This indicates the high engagement of these participants with the AM FB group.

### *Paralinguistic features*

Findings in this study shows the two most utilised paralinguistic features in the AM FB group are the 'Like' and 'Feeling' buttons. 'Like' has been cited as a way to extend support on the status posted by the parents on the AM FB *wall*. It makes extending social support easier - just click 'Like' on someone's post of their achievement, instead of being the 15th person to say congratulations (Frier, 2016). When the parents first join the AM FB support group, the number of 'Likes' matters to them as it is an indication of how many members read the status and offer their support. This can be supported by the claim that clicking on the 'Like' button, with a significant number of 'Likes' and comments posted on specific content on the Facebook page provides solid evidence of users' engagement (Glazer, 2012). Those who have been members of the group for three years and more realised the effect of 'Like', especially to newer members, and thus motivates them to click on the 'Like' often. The former, however, go through a transition from participating in the communication in the AM FB group, preferring to get 'Comment' rather than just 'Like'. Even a single sentence of comment becomes a boost of support to these parents who have been in the AM FB group for some time. These responses via 'Like' and 'Comment' buttons may be used as crucial metrics for measuring the effectiveness of online events (Ellison et al., 2007) which can also be applied to determine the effectiveness of the AM FB support group to its members.

The effects of 'Like' are mostly studied in the area of online business, marketing and celebrity fan pages. The result shows that the number of 'Likes' on a brand page is an indication of users' engagement and it increases the brand visibility to other users who are not on the brand page. (Cvijikj & Michahelles, 2013). This could also be applied to this

study where the number of 'Likes' is a sign of the parents' engagement and clicking 'Like' is an indication of support which is likely to increase the self-esteem of the parents who received the 'Like'. This is due to the claim that people with low self-esteem are more likely to use the internet more frequently (Mesch, 2006). This claim could be applied to this study as result shows that the participants reported having low self-esteem when initially joining the AM FB group. Hence, the 'Like' that they receive could boost their self-esteem. In Facebook, members of a *Group* can respond to a post on the *wall* by clicking the 'Like' button to indicate support to a message or simply "have read." They can also write opinions to a post using the 'Comment' function and 'Share' their opinions to specific online friends, groups, or the public (Wilson, Sala, Puttuswamy, & Zhao, 2009). A lot of research had looked into the number of 'Like' being clicked on certain posts, and the frequency of 'Comments' posted on the *wall* especially for the Facebook page which indicates fans' engagement as well as anecdotes posted by users on a fan page *wall* (Glazer, 2012).

The 'Feeling' button is another paralinguistic feature in Facebook which could compensate for the absence of the users' physical sign of facial expression. Apart from the use of language to express how they feel in the status update, these parents use this feature to accentuate their feelings. This is a new strategy of communication in the online world (Morgan & Symon, 2004) and this new symbolic language marks resemblance to the word (Williams & Robson, 2003) to compensate for the lack of physical presence or touches on the internet. However, surprisingly this paralinguistic feature is not as well-researched as the 'Like' button, perhaps because it may not have the similar effect as the 'Like' button would provide. In contrast, in the context of a support group, the researcher believes that this 'Feeling' button is crucial when used by the participants when posting a status as it actually intensifies the feelings that they are experiencing at the time they post it. Although the effect of this paralinguistic feature may not be great, it does affect the moods of other members who read the status containing the 'Feeling' emoticon.

### *Linguistic features/language use*

Although the AM FB *wall* is a public space in which the members can post anything they desire, it is ironically a personal space which the users open up to the public by posting the status on the *wall*. It is considered as a personal space due to the profile, profile picture and the content of the status that the user exposes to other members of the group. Hence, whatever the content that is written in the status vitally reflects the personality of the user writing and posting it. Due to this, the participants in this study give due consideration to the choice of words to be used when writing a status before posting it to the AM FB *wall*. Findings in this study suggests that parents use the strategy of planning, writing and editing before posting a status to ensure that it would not offend other parents in the group. This act of carefully writing a status, as not to offend anyone, was applied both for the post with a negative note and positive note, which the latter is a shocking finding due to the fact that the AM FB group is indeed a support group. Language use is paramount when writing the status as the “shift of human interactions, socialisation and communication activities towards online platforms means that managing the impression of one’s online presence is increasingly important” (Bachrach et al., 2012, p. 24). This strategy can be supported by the claim that users take extra care when constructing a message or status expressions by editing, revising or abandoning their ideas until they create acceptable and pleasing impressions on other users (Henderson & Gilding, 2004; Walther, 1996b; Walther, 2006). Thus, word choice helps in illustrating the parents’ lasting impression from other members in the AM FB group. The language use on the AM FB *wall* by these participants could also inform the researcher of their language behaviour offline. This claim is made as language use on Facebook reflects the wider language context and there is a link between the language used with friends offline and the language used on Facebook (Cunliffe, Morris, & Prys, 2013). Thus, this could explain the parents’ behaviour in terms of the language used both online and offline.

### *Synchronous and asynchronous communication*

As stated earlier, Facebook is an online platform that allows both communicative features to be used simultaneously. Findings in this study show both asynchronous and synchronous communication offered by Facebook are fully utilised by the participants in the AM FB group. Although both provide advantages as they allow the parents to communicate in order to seek and obtain support from other members, synchronous communication does provide a shocking finding. Some parents misuse it to criticise and express dissatisfaction to other parents over the status posted by the latter on the AM FB *wall*. It is appalling to find this in a Facebook group meant for social support. This is because the criticisms made could be damaging and in fact adding to the emotional stress that the parents who receive the critics are already experiencing. Despite this, the majority of the participants use the private messaging feature wisely to connect further with other parents in the group, particularly with those who they have identified as having lots of experience managing their child with ASD.

Asynchronous communicative feature in Facebook is fully utilised by the participants and this is proven by the frequency of activities conducted on the AM FB wall. Asynchronous communication occurs when other parents post a 'Comment' and click the 'Like' or 'Share' button on the status posted by the participants. These communication strategies are the indication of how social support is given by others and exchanges of support occur when the one who posted the status replies to the comments given. Although the one who posted the status may have to wait for some time for responses from others, the participants feel that it is worthwhile as the responses they obtain assisted in the social support that they seek. This can be supported by the claim made by Beaudoin and Tao (2007) that asynchronous communication helps alleviate depression, coping and stress for cancer patients using Yahoo! cancer-related discussion group as in the model in Figure 5.1 below. Synchronous online communication, however, is not included in the model perhaps because

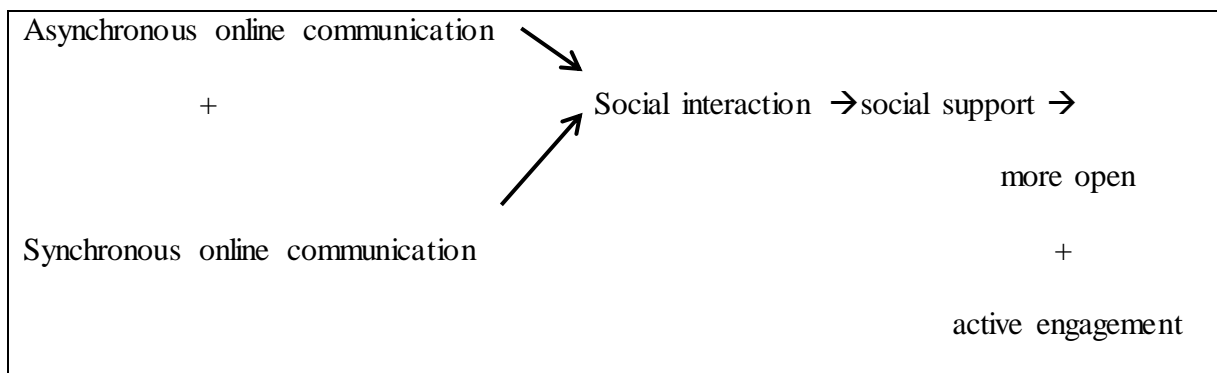
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of the platform used which are the chat rooms and instant-messaging that lacks a consistent mass and continuity of the participants.

Asynchronous online communication → Social interaction → Social support  
→ Positive health outcomes

*Figure 5.1.* Model of asynchronous online communication in support group.

Thus, the major findings in this study regarding means of communication could add to the existing model above as both synchronous and asynchronous communication in the AM FB group promote social interaction which leads to social support and later resulted in the parents becoming more open about their child by engaging actively on the AM FB wall (Figure 5.2). This could also indicate the parents' satisfaction over the support gained from members of the AM FB group that they become more open and actively engaged communicating in the group and previous research have identified satisfaction with one's support network to be a more reliable predictor of positive social and psychological outcomes than the size of one's support network (Query & Wright, 2003; Wright, Banas, et al., 2010).



*Figure 5.2.* Model of means of communication in Facebook social support group.



**5.2 Objective 2: To investigate the impact of online engagement in Autisme Malaysia Facebook support group on parents of a child with ASD in Malaysia.**

5.2.1 Research Questions: a) To what extent does communicating support in Autisme Malaysia Facebook support group benefiting or damaging to parents of a child with ASD in Malaysia?

It has been discussed earlier that social support either informational, emotional and religious, is evident in the AM FB group and is frequently exchanged by its members. This communicating support in the AM FB support group has affected the participants greatly. The effect is benefiting as they are able to express their feelings openly without the fear of being stigmatised. The participants reported the freedom to express both positive and negative feelings, especially the latter, as the AM FB group is the only platform where other members understand what each parent goes through. This is justified by the view that social media is one of the technologies which allow individuals to express themselves freely in cyberspace (Takashi et al, 2003). After a period of time communicating negative feelings, the participants go through a transition that leads to positive improvements. The positive improvement is reflected not just on the parents but the child as well. More positive feelings are shared on the *wall*, particularly involving positive improvements made by the child. It is shocking, however, to find that despite this transition, the parents encounter negative perceptions from other parents in the AM FB group. This demonstrates that communicating support on the AM FB *wall* can also be damaging to these parents.

***Expression of feelings***

Social networking site has been illustrated to offer a myriad of uses and benefits but presently does not offer an explicit expression of a well-being state of the individual and others (André, Schraefel, Dix, & White, 2011). It should be utilised more than just for a

phatic communication of asking 'how are you'. This claim can be contested in this study as findings suggest that the participants fully utilise the Facebook platform to communicate their feelings, both positive and negative. Writing anecdote or narratives has been a strategy used by the parents either to express both positive and negative feelings or to share improvement made by the child. This is aligned with the study by Bar-Lev (2008) that HIV/AIDS patients who write detailed descriptions of their illness experiences would create emotionally vibrant and empathic communities in the online support groups.

### *Negative feelings*

It has been stated that most participants express more negative feelings when they first started communicating on the AM FB *wall*. This is indeed one of the benefits of communicating support. Disappointment, anxiety and sadness are the three most negative feelings being expressed by the parents when they start posting statuses on the *wall*. This finding is consistent with another study in which parents of a child with disabilities are reported to experience anxiety, depression, guilt, low self-esteem and low personal satisfaction due to having such a child (Sunay, 2000). Feeling of guilt is commonly associated with self-efficacy (feelings of competence in the parental role) among mothers of a child with autism (Kuhn & Carter, 2006). It means that mothers dwell in guilt due to their feeling of incompetence dealing with the child. Findings in this study are also congruent with a study that reported difficult temperament of children with ASD contribute to more negative than positive impacts on Swedish parents (Boström, Broberg, & Hwang, 2010). Thus, it seems that children with ASD in the severe spectrum do contribute to the negative impact on the parents regardless of the ethnicity of the parents.

It seems that coming from the same cultural background, these participants share the same negative feelings perhaps due to the emotional stress of not just having the child with ASD but the lack of knowledge in managing and parenting such a child. It is claimed that cultural background may also influence a parents' interpretation of the child's symptoms,

the manner in which a parent responds to such symptoms, and the manner in which a parent communicates such symptoms to a professional (Mandell & Novak, 2005). It could be that due to these consequences, these parents prefer to involve in computer-mediated communication (CMC) with Facebook becoming the platform. In the CMC settings, the parents are able to participate in (i) one-to-one communication; (ii) one-to-many interactions, and (iii) intergroup discussions (Baron, 2010; Herring, 2007). Burgess and Green (2009) recently argued that “YouTube is a potential site of cosmopolitan cultural citizenship – a space in which individuals can represent their identities and perspectives, engage with the self-representations of others, and encounter cultural difference” (p. 81). Facebook also provides similar platform as YouTube. Although most of the Malay communities are Muslims who are supposed to possess high spirituality due to their religious beliefs, these parents display otherwise. This is contradictory to the African-American communities who also value interdependence, religiosity, and spirituality, but strong kinship networks may protect them against experiencing negative impact of having a child with autism (Brooks et al., 2004). In that study, however, the education of the parents is not indicated as in another study (Carr & Lord, 2013) which found that “African-American mothers with lower education perceived caring for a child with autism as less of a burden and more of an accepted familial obligation” (p. 413). Regardless of these differences in views, the participants in this study still perceive sharing similar negative feelings is a benefit of communicating support.

Another interesting finding is the preference of these participants to express their negative feelings on the AM FB *wall* rather than on their personal Facebook *wall*. This denotes the benefits of communicating support on these participants. It seems that the members of the former are more receptive compared to friends in the latter. The responses that these parents obtain in the former are more positive unlike the latter which usually come in a form of questions about the child’s condition. These questions from friends who seem to

not understand what is autism are so overwhelming for these parents that they favour the AM FB *wall* as a platform for expressing negative feelings. This can be supported by the claim that individuals contribute less, in fear of embarrassment, which is particularly dominant on social network sites where users may be concerned about impressions given, sometimes unintentionally, to family, friends, co-workers and acquaintances (Morris et al., 2010; Newman et al., 2011). Another justification is that many individuals find it difficult to obtain appropriate support from strong ties (such as close friends and family members) because they feel that these potential sources of support lack experience or have limited information about certain problems, or they feel uncomfortable discussing their sensitive problems with members of their close tie support network because of the fear of being judged or patronized (Albrecht, Burleson, & Goldsmith, 1994; Brashers et al., 2004; Kevin et al., 2013). Thus, this explains the predicament that the parents face for not sharing matters related to their child with ASD on their own personal Facebook page as their ‘friends’ are mostly family members, close friends and colleagues who do not share the same experience and do not have a child with ASD. Hence, seeking support from the AM FB *wall* outweighs more benefits than communicating it on their personal FB *wall*.

### ***Transition from negative to positive***

The findings suggest that there is a shift of feelings being expressed by the parents on the AM FB *wall* in which they started off negative and later to more positive after being members of the Facebook support group for a period of time. This transition experienced by the participants is an indication of how the Autisme Malaysia Facebook group is a powerful and influential tool to change the perspective of these parents on having a child with ASD. Not only does their perspective change to be more positive, the effect could also be seen on the child as the change has made most of these parents to be more determined to give the best to the latter. This is consistent with a study among parents of a child with Cornelia de Lange syndrome (CdLS) which shows that majority of them “reported that ISGs have been

helpful in finding emotional support, with the most common areas impacted as a result of ISG participation being behaviour toward their children and family dynamic” (Cacioppo et al., 2016, p. 229). This frequent expression of negative feelings contradicts the study among the well-educated and economically-advantaged White participants who seldom express overtly hostile or highly critical statements about their child with autism, even in cases where the child demonstrates marked impairment or behaviour problems. This study by Benson, Daley, Karlof, and Robison (2011) in the United States claimed that “mothers express strong feelings of warmth, appreciation, and love related to favourable child outcomes despite the many challenges that may affect the mother–child relationship” (p. 77). In comparison to the study of the parents in the AM FB group, since the demographic data does not ask for their social and economic (SES) background, it could not be concluded if their expression of negative feeling is related to their SES status. It can be said, however, that there is a similarity of this study in the context of Malaysia to the USA study as the parents in both studies express positive feelings related to favourable child outcomes. Thus, this can justify the parental expression of gratitude, hope and wishes, and happiness and excitement on the AM FB *wall*.

Expressing feelings, particularly positive emotions as in this study is indeed beneficial to the participants as it is a better, easier and more readily-available catalyst of online technology that encourages users to network and develop relationships online as content alone is not enough. The positive emotions being expressed on the AM FB *wall* show how these parents display a sense of acceptance and maturity in dealing with the child with ASD as their active participation moulds their behaviour (Campbell, 2008). The transition that the participants experience assisted in the behaviour change as they become more open to various possibilities and endless efforts in parenting the child. They no longer feel stigmatised for having the child and happy to help increase the awareness of ASD among the general public in Malaysia. The feelings of shame and guilt are now being

replaced with pride and determination for the betterment of the child as can be seen in various postings made by parents sharing the children's improvements.

The positive improvement shown by their child with ASD could perhaps be driven by the transition of the participants' feelings from negative to positive. The improvement is indirectly reflected in how the parents' changed of perspective results in their changes of parenting that leads to the child's behaviour improvement, for example. This can be justified by the claim that the interplay between the improvement of children with disability and the effects on family dynamics is considered as a major impact (Brown et al., 2011) of the parents' change of perspectives. This is because the child with a disability who does not get sufficient support will have major negative effects on the parents and other family members such as other siblings in which behavioural challenges have been cited as the most impacting on family relations (Rillotta, Kirby, & Shearer, 2010). As in the context of the parents in the AM FB group, the social support they gain online alleviates the child's behavioural challenges as the former is able to learn other measures or ways of parenting from other parents and try them on their own. Thus, it can be claimed that the engagement with the AM FB group has directly offered support that these parents desire and consequently changes how they view and manage the child, which later benefitted both the children and themselves.

This sharing of positive improvements, which is beneficial to these participants, in contrast, has become damaging to them. This is due to other members having negative perceptions on the status showing their child's improvements. Some parents have the audacity to send private messages to those parents sharing the proud moments on the AM FB wall, criticising the latter of being arrogant for showing off what their child is able to achieve. Hence, some participants who receive such responses feel taken aback and stressful as others perceive their sharing as negative. This eventually does not hamper them to continue sharing as the positive responses they receive in the 'Comment' outweigh the

negative perception from those few parents. This is further discussed when discussing discursive struggle among the participants later.

### 5.2.2 Research question: b) In what way do these impacts affect parents' personally or professionally/as individuals or members of the online community?

There will be two parts of discussions to answer this research question, (i) the positive impact, and (ii) the negative impacts. The first part of the discussion refers to the positive impacts which are divided into (a) parents as individuals and (b) parents as a society. Findings of the impacts of the AM FB group on the parents of a child with ASD in Malaysia can be supported by the claim that social support resulted in both positive and negative outcomes predominantly in mothers of a child with ASD in the past studies (Ekas et al., 2010; Smith et al., 2012). Those parents who realise the positive impacts on them are the ones who participate actively in the AM FB group, synchronously and asynchronously. This can be justified as there is ample evidence showing support groups have frequently resulted in positive impacts on those who participated in online social support exchanges (Maloney-Krichmar & Preece, 2005; Preece, 2000; Wicks et al., 2010). The second part which is the negative impact deals with negative perceptions and obstructed freedom of speech.

#### ***Positive impacts on parents as individuals***

The findings on the positive impacts which affect the participants in the AM FB group are congruent with other studies on online support groups using other platforms, such as e-mails and bulletin boards, in which they serve as multiple communication purposes. It is found that cancer patients using online forum discussion reported positive attitudes towards the online support group as it provides them with emotional support, interactions, and information (Im et al., 2007). Babinski, Jones, and DeWert (2001), for example, analysed online forums in an online support group for new teachers and found that the content reflected fostering a sense of community (34.8%) or providing advice

(21.3%), sharing knowledge (20.1%), relating a personal experience with the issue (16.0%), and encouraging reflection (7.9%). All the five themes are applicable to this study including encouraging reflection which can be seen when parents dwell in self-guilt over parenting the child with ASD, such as reprimanding the child for misbehaving. The two most cited positive effects felt personally by participants are emotional strength and increased self-esteem.

### ***Became emotionally strong***

The ability to express feelings without being stigmatised commonly affects the participants' emotionally. Findings suggest that the participants who engage actively in the AM FB group through communicating synchronously and asynchronously become emotionally strong as they are now more knowledgeable on how to manage their child and their own self, particularly their emotions. Having the sense of belonging to the group makes them feel bonded with the other members, and that consequently they are able to control their emotions. The impacts of the sense of belonging and restructuring life are consistent with the findings that face-to-face support group has on the interpersonal and intra-individual domains of the support group members, respectively (Solomon et al., 2001). The finding in this study is also consistent with those studies (Wright & Bell, 2003; Wright & Miller, 2010) which found that computer-mediated social support helps in reducing depression for individuals who are socially isolated or living with a stigmatised health condition, such as HIV/AIDS or a disability. The support which comes as positive and encouraging comments influences the parents' emotion and results in increasing their self-esteem. This can be justified by a research studying the impact of positive messages on psychological development which resulted in promoting users' positive attitudes towards future developments and social influence (Chang, Lin, Lin, Chang, & Chong, 2014). Therefore, positive messages on Facebook lead to positive attitudes of these parents which consequently promote positive emotions.



The participants in this study also reported that they become emotionally strong as the support gained assists in alleviating their stress due to challenges faced in managing the child with ASD. This is congruent with the findings of other studies on parents of a child with ASD in which higher levels of social support have been associated with lower levels of negative impact (Bishop et al., 2007), psychological distress (Bromley et al., 2004), negative mood (Pottie et al., 2009), and depressive symptoms (Benson & Karlof, 2009; Ekas et al., 2010; Weiss et al., 2013). Conversely, recent work has found that parents who experience a higher level of social support also reported a higher level of positive mood (Ekas et al., 2010; Pottie et al., 2009) and improved mental and physical health (Uchino et al., 2012), be it offline or online. Thus, the participants become emotionally strong as a result of the positive impact communicating support through expressing feelings in the AM FB group.

It is highlighted in Chapter 4 that the impact of becoming emotionally strong is very closely related to the sense of guilt or self-blame. The guilt or self-blame triggers the parents to realise the past mistakes that they have done in managing the child and promised not to repeat them, which they commonly express on the AM FB *wall*. However, this self-guilt or self-blame is quickly brushed aside by other members who used to have similar feelings and later offering emotional support so that the former no longer possess such feelings. This is consistent with a study (Kim et al., 2011) indicating individuals with lower levels of self-blame are more likely to provide emotional support in online settings. This contributes to the frequently occurred social support exchanges on the AM FB *wall* as can be seen in the participants' observation sheet.

### ***Increased self-esteem***

As highlighted in the findings, by expressing feelings and sharing improvements, the parents who participated actively in the AM FB support group felt an increase of self-esteem in parenting and managing themselves and their child compared to before joining the group. This positive impact is reported by the participants in this study as it gives a great effect on

them personally. This is congruent with a study on pregnant women having depression (Chiu et al., 2015) which claimed that online social support has a positive effect on self-efficacy, self-esteem and subjective well-being of the individuals. Bandura (1977) defined self-efficacy as “beliefs in one's capabilities to organise and execute the courses of action required to produce given attainments” (p. 191). In this study, self-efficacy is the belief in one's competence to cope with stressful or challenging demands (Schwarzer & Jerusalem, 1995) of having a child with ASD. Bandura (1994) believed that people with high self-efficacy set themselves challenging goals, maintain a strong commitment to these goals, and heighten and sustain their efforts in the face of failure. This is evident among the participants of this study as most of them engage in self-determination to ensure that their child gets the best intervention which is vital for their future. By expressing and sharing actively in the AM FB support group, they are able to quickly recover their sense of self-efficacy after experiencing their own failures or setbacks and also reading others' experience on the AM FB *wall*. They become more optimistic about their personal capabilities to empower challenging situations by adopting or adapting other parents' experience that have gone through similar experiences. Such self-beliefs produce personal accomplishments, reduce stress and foster positive well-being (Chiu et al., 2015). Self-efficacy has also been linked to well-being, for example, individuals high in social self-efficacy are more likely to report higher levels of well-being in the context of online communication (Li, Shi, & Dang, 2014) and successfully managing their child's problematic behaviours (Hastings & Beck, 2004; Singer et al., 2007). Hence, the same can be said for the parents of a child with ASD in the AM FB support group.

Lack of knowledge and receiving social stigma are the contributors to the parents of a child with ASD in Malaysia having low self-esteem and these are gradually diminished when they become highly active with the AM FB group. Having increased self-esteem gives them a sense of empowerment to make known judgements and decisions regarding their

child's wellbeing. This could contradict the finding by Forest and Wood (2012, p. 295) that "people with low self-esteem considered Facebook an appealing venue for self-disclosure, but the low positivity and high negativity of their disclosures elicited undesirable responses from other people". The parents who have been with the AM FB support group for a period of time have the ability and skill to manage the undesirable responses that make their self-esteem increase. This is discussed more in-depth in the negative perception heading. High self-esteem could lead to the parents having great confidence in managing themselves emotionally and spiritually which leads to accepting the child as special and later making wise decisions and actions regarding their child's wellbeing. This is supported by Baumeister et al (2003, p. 19) that "high self-esteem might give a person the confidence and initiative to take charge of a group, make decisions under pressure or uncertainty, and expect that others will do his or her bidding". It seems Baumeister (2003) is suggesting that people with high self-esteem could be dominating a group and trying to lead others the way they want, which could be beneficial to the group or otherwise. This is evident in the AM FB group as this is practised by most of the admins in the group for the benefit of other members (as highlighted by the admins during the semi-structure interview). Although there are issues raised by other unsatisfied parents over the admins' action in controlling the conversation thread, others seem to be accepting and conforming to the admins' actions.

Findings in this study also suggested that most participants displayed high self-esteem when sharing anecdotes about their child, particularly about their child's achievement. These parents in the high-risk support group such as the AM FB group, did need a boost of self-esteem to help their own selves and their child. As highlighted earlier, most parents who just joined the group had low self-esteem, particularly when society had a social stigma and lack of awareness about ASD. A study on Hispanic mothers having children with ASD revealed that the Hispanic community regarded them as 'bad mothers' due to the community's lack of awareness about ASD and their judgement on the behaviour

of the child in public places (Breithaupt, Thomas, Wong, Mesibov, & Morrissey, 2015). Thus, this claim illustrates the same feelings that parents in the AM FB group experienced as both the Hispanic and Malay communities are not White. Although having parents with high self-esteem in a Facebook support group such as AM benefitted the parents personally, it may also be damaging as “people with high self-esteem in groups are more willing than those with low self-esteem to speak up to criticize the group or propose directions for action” (Baumeister et al., 2003, p. 21). A similar claim is shared by Fein and Spencer (1997) that the opportunity to discriminate against a member of a negatively stereotyped group, such as disabilities group, can bolster self-esteem. This could be seen when other parents openly criticise others on the comment thread on the AM FB *wall* as this might indicate the former have high self-esteem and that they are trying to influence others to agree with what they believe in. One good example is when the parents tried to influence other members to not vaccinate their child, fearing that vaccination is the cause of ASD. If this occurs, the admin would intervene and practise their authority to delete the post and write a gentle reminder on the AM FB *wall* so that members are aware of the groups’ rules. Therefore, it can be claimed that having members with increased self-esteem can be both benefitting and damaging to the online group. It depends on how the parents themselves put it to good use or otherwise as what they write on the AM FB *wall* will portray their actual behaviour.

### ***Positive impacts on parents as members of online community***

When joining a group, be it online or offline, the individuals have responsibilities towards the group. The way they behave and act in the group is a reflection of their personalities, although there are contrasting views between how individuals behave online with their real behaviour offline. In this study, the participants as members of the online community reported the sense of responsibilities towards the group and also increasing awareness as part of the effects they obtained from the positive impacts of communicating in the AM FB group.

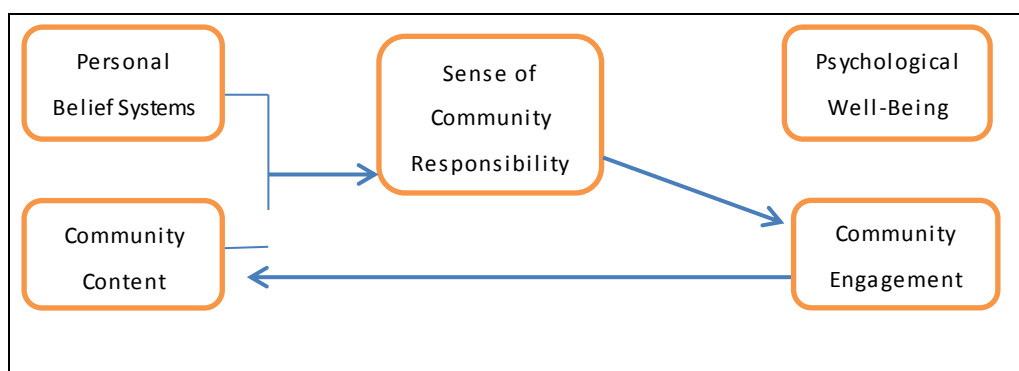
### Sense of Community as Responsibility

Findings in this study suggest that the participants feel such a strong sense of belonging and bonding that they feel obliged to extend social support to others in the same way they are previously supported socially. This obligation is seen as a responsibility that the participants need to fulfil so that those parents who are new to the group will not go through the same painful experience in terms of battling emotions and getting information. All these senses are closely related to the sense of community. The sense of community (SOC) framework comprises four-factor model in terms of needs fulfilment, membership and participation, influence, and shared emotional association (Mannarini & Fedi, 2009; McMillan & Chavis, 1986). This framework is further divided into the theory of community as resource and theory of community as responsibility. The former views community as a resource to fulfil the psychological and physiological needs for belonging, influence and connection (Talò, Mannarini, & Rochira, 2014) such that when these participants participate in the AM FB support group and their needs are fulfilled, they generally feel better and feel great in relation to the online community. Due to the positive impact of expressing and sharing, all the twelve participants are happy and satisfied about joining the group as they have learnt a lot about ASD and this has changed their perspective and view of their own life. “The level of satisfaction of the individuals in the community experience depends on their sense of community responsibility and it is the more powerful predictor in explaining higher order engagement requiring a greater investment of time and resources” (Nowell & Boyd, 2014, p. 240). The social media platforms are claimed to be ‘commonly supportive and provided a sense of community’ among young people who were previously involved in deliberate self-harm acts (Dyson et al., 2016). The findings in the study showed 8 of the 12 participants spend a few hours every day in the AM FB group to read all the statuses and post comments whenever possible, which is an indication of the high level of community responsibility. This explains why they are willing to spend their time and resources on the

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Facebook group. In fact, it has become a sense of obligation for them to respond to the questions posted on the AM FB wall. The satisfaction gained from extending assistance and sharing knowledge and experience is to ensure that others would not go through the same challenging experience as they have been previously. This leads to these participants' psychological well-being knowing that they could provide social support to others in the group.

Many studies support the positive relationship between the fulfilled needs and psychological well-being of the community members in the theory of community as a resource (Albanesi, Cicognani, & Zani, 2007; Farrell, Aubry, & Coulombe, 2004; Jorgensen, Jamieson, & Martin, 2010). However, there is a claim that one's personal belief systems which describe how one interacts (through appropriate behaviours) within a community encourages community engagement but has no strong positive impact on the person's psychological well-being (Nowell & Boyd, 2014) (refer Figure 5.3). This theory views individuals' personal values and beliefs of who they are and how to behave in a given social context are influenced by exposure to and embedded within various institutions such as families, schools, workplace and social groups (Weick, Sutcliffe, & Obstfeld, 2005). Individuals use their personal values and beliefs as a guide in shaping their behaviour through interaction and engagement in that particular social context. The sense of responsibility for a community can only be implied when the individuals take action which is consistent with their own beliefs or able to alter their beliefs (Gawronski, 2012).



*Figure 5.3. A theory of community as responsibility (Nowell & Boyd, 2011).*

In the context of the AM FB support group, however, this theory can be debated as there is a strong impact of sense of community responsibility with psychological well-being of its members. In fact, community engagement can be said to be a catalyst to the individuals' psychological well-being in the context of this study. The psychological well-being can be indicated through outcomes such as life satisfaction (Erdogan, Bauer, Truxillo, & Mansfield, 2012) social identity (Dutton, Roberts, & Bednar, 2010), engagement (Mitchell, Stone-Wiggins, Stevenson, & Florin, 2004), depression, parenting stress, family resilience, and family adjustment (Benzies et al., 2011). All these outcomes are evident in this study. Although psychological well-being is not the focus of this study, the findings emerged from the data are significant and this view could be used to support it. Due to the social support gained from the AM FB group, all the twelve participants reported a change of view towards their child with ASD as they believe the challenges of managing and parenting them can be overcome with a positive attitude. This is supported by another study (Benzies et al., 2011) in which "the meaning parents make of childhood disability affects their family life and family well-being resulting in most mothers respond to the challenge of childhood disability with positive coping and resiliency" (p. 154) and a decrease in reported mental health problems in mothers (Barker et al., 2011; Sawyer et al., 2010). Similar findings on positive associations between online social network use (Facebook, in particular) and well-being have been reported by Valenzuela, Park & Kee (2009a). The findings of this study also dismisses the study (Chou & Edge, 2012; Huang, 2010; Kross et al., 2013) that prolonged use of Facebook resulted in negative shifts in the users' well-being, both on day-to-day basis and satisfaction over their life, as they became unhappy and their life satisfaction declined. This is because, over a period of time participating and communicating actively in the AM FB support group, the participants have a more positive outlook over their own self (such as parenting and managing the child with ASD) and the child's future.

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In much later discussion of negative impact, there is an indication where the AM FB support group triggers damaging social comparisons (Chou & Edge, 2012; Haferkamp & Kramer, 2011) which in a way affect the parents' well-being, but the damage is minimised by the comments made by other parents or the admins of the group on the AM FB *wall*.

Another sense of community responsibility can be seen from the use of the participants' real photos as their Facebook profiles. Facebook profiles can be said to illustrate a user's identity and "the fact that people can judge each other's personality based on them implies two things: an individual's personality is manifested on their Facebook profile, and some aspects of Facebook profiles are used by people to judge others' personalities" (Bachrach et al., 2012, p. 25). Due to this notion, the members in the AM FB group bring their personal values and beliefs into the online support group by firstly using their own name and picture as a Facebook profile. This implies their belief in trusting the online group as a platform for them to learn, share and support each other. This practice is against the claim that Facebook users tend to be anonymous by using an avatar as their profile so that the impact of social norms on the users could be diminished (Rolland & Parmentier, 2013). On the contrary, participation in public life in the real world demands that people develop a sense of social norms, learn to navigate social relations, and begin to understand society at large and this could easily be accomplished online when users develop strategies to assert control over social situations by being anonymous and using avatars (boyd & Marwick, 2011). This is further supported by the claim that there was a broad assumption, supported by content analysis that social network profiles were used to create and communicate idealised selves (Manago et al., 2008), which users would not achieve in the real world. The findings in this study also contradict the findings in other studies (Cobb et al., 2010; Maloney-Krichmar & Preece, 2005) that those who always contribute to the online communities are members who are successful with their behaviour change and yet their profiles still remain anonymous. The practice of using avatars or remaining anonymous



denotes the members trying to avoid being discriminated by others and also allows the freedom for them to post any negative comments and create controversies. This is further supported by the past research that had highlighted anonymity is an advantage of joining an online community support group as members, particularly those who are disabled, need not disclose themselves to others due to being ashamed or having low self-esteem (VanLear et al., 2005). However, this notion can be debated as the participants in this study do not become anonymous although most of them have low self-esteem for having a child with ASD.

In addition, the information that the users disclose online, the status updates and comments made to others may be all the indications of their online behaviours. Although there are claims that individuals illustrate different online identities from their offline selves (boyd & Marwick, 2011) for various reasons such as privacy, or even malicious intention (Huberty, 2015), this does not apply to members in the AM FB support group as most prefer not to use the avatar as their profile pictures. As their online behaviours are shaped by other institutions (Weick et al., 2005) which are mostly offline, it is claimed that what is shown on Facebook reflects the actual personality of its user rather than an idealised projection of desired or made-up traits (Back et al., 2010). The result of the study by Backs et al (2010) suggested that “people are not using their OSN profiles to promote an idealised virtual identity” (p. 374), instead, OSNs might be an efficient medium for expressing and communicating real personality, which may help explain the popularity of Facebook. Thus, it could be said that the parents’ behaviour in the AM FB group is a reflection of their self-behaviour offline. Due to this, most parents are cautious when posting or commenting on the *wall* as their real pictures and names are clearly displayed. Choosing to use real picture rather than the avatar shows the parents’ high level of trustworthy towards the Facebook group and also other members of the group.

In a face-to-face setting, Ekas et al (2010) claimed that “a solid social support network may promote a more optimistic outlook on life that, in turn, fosters well-being” (p. 1275). When the individuals feel loved and supported, their cognitive representations about the future may be changed. This can also be applied to the online setting, as in this study, the participants highlighted that great social support obtained through the AM FB group have made them change their views towards what the future may hold for their child. This can be seen from the positive impacts which were discussed in Chapter 4. They have passed the stage of denial, begin to accept the child as special and adapt to the needs of the child by making changes to their own life. The idea of well-being in a face-to-face community context also claims that sense of community predicts social well-being and in order to increase the latter, it is pivotal to offer more opportunities for the members to experience a sense of belonging to the group and promote prosocial behaviours (Albanesi et al., 2007). According to Eisenberg and Mussen (1989), “Prosocial behaviours refer to voluntary actions that are intended to help or benefit another individual or group of individuals” (p. 3). It illustrates the impact of the individual’s actions including activities such as sharing, comforting, rescuing, and helping. Although the idea behind this concept appeals to children, it could still be applied to adolescents and adults. In the context of a support group, these prosocial behaviours affect not only other group members but the individuals themselves. That is how the social well-being is increased due to the high sense of belonging to the group members. Figure 5.4 summarises the proposed theory based on Nowell and Boyd (2011), related to the context of the AM FB group.

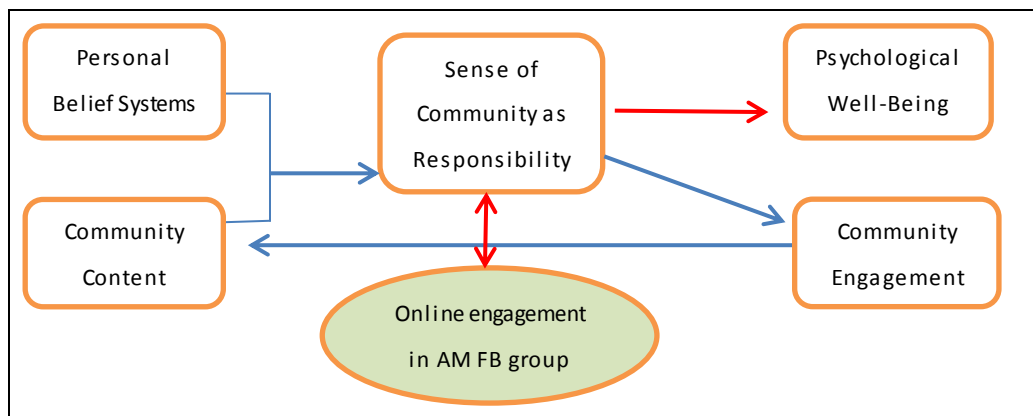


Figure 5.4. Proposed theory of sense of community as responsibility based on findings from the AM FB group.

### ***Increasing awareness***

Findings in this study also suggest that increased awareness and application into real life are the effects the participants experienced as a result of expressing and sharing on the AM FB *wall*. These, in turn, inspire them to create and increase awareness among the members in the group regarding issues related to ASD. Some of the issues that require great attention and awareness are vaccination, supplements to ‘cure’ ASD and the governmental policies. Sharing these issues on the *wall* creates awareness among the parents so that they would not be left behind with the updated matters concerning ASD in Malaysia. Consequently, this increased awareness is further extended to offline involving the general public as the parents feel the urge to explain what ASD is to others so that the child with ASD could be accepted and the social stigma surrounding ASD could be reduced.

The issues on vaccination and health supplements, for example, are the most debatable topic on the AM FB *wall*. Newly-joined parents, those mostly in doubt over their child’s condition would frequently raise these issues. The participants in this study who have been members for three years and more would give comments so that these parents are aware of the uncertainties surrounding vaccination and health supplements as both are not clinically proven to cause or ‘cure’ ASD accordingly. The level of awareness on these issues increases due to the participants’ active role in offering informational support. Their act can

be justified as the members practice online community citizenship behaviour, which includes “showing concern for the development of the online support community, suggesting positive changes to the community, helping other members solve their problems, and showing courtesy toward other members” (Chiu et al., 2015, p. 504). All these behaviours shape the individuals, which consequently positively impact the AM FB support group as a whole. These behaviours also increase parent’s perceptions of their parenting skills which may “decrease experiences of parenting stress and assist parents in their roles as therapists and co-therapists, and with decisions surrounding their child’s treatment and future” (McStay et al., 2014, p. 508). Planning for the child’s future is also one of the crucial needs for the participants in this study, which is consistent with a study (Bromley et al., 2004) that highlighted 69% of mothers of a child with ASD in the UK perceived future planning as crucial. Thus, all these help the parents on the AM FB group to be more aware of the debatable issues and enabled them to make wise decisions on vaccination and health supplements.

Findings also showed that sharing of experiences on the AM FB wall has increased the awareness of the participants on the governmental policies, including the change of disability card, allowances for the child and work flexibility for parents of a child with ASD. The participants in this study hope for better service and more stringent policies from the Malaysian government to assist the ASD community which may be far-fetched, but they remain vigilant that it will happen one day. It is not impossible as the French parents’ associations had indeed influenced the change in public policies as constant pressure was put on the French government. In 1995, a new policy was introduced to keep with the demands of the parents’ associations of children with ASD in France, which included “development of an early diagnosis, the evaluation of a more rigorous treatment and the modification of intervention programmes by adopting a more educational and behavioural approach involving the parents’ collaboration” (Chamak, 2008, p. 84). Websites, colloquia, reports,

newsletters, contact with the media and judicial recourse are the mediums used by this parents' association to escalate its impact. Hence, the same impact might take place in Malaysia, perhaps through the AM FB support group. Although the AM FB support group does not specifically implement interventions for these parents, the exchanges of support both synchronously and asynchronously would somehow replicate a delivery system which is highlighted as lacking in the Malaysian setting. These exchanges can help parents to better emphasise their specific needs, identify the strengths and weaknesses of their social networks, and mobilise their networks when needed (Hansell et al., 1998) as that of a delivery system. Other factors contributing to the success of the AM FB group are the type and quality of support offered, the person providing the assistance, and contextual issues (Ekas et al., 2010) being discussed openly on the Facebook *wall*. All these are achieved effectively through the active participation of these participants communicating on the AM FB support group.

### ***Negative impacts of the AM FB Support Group***

The negative impacts of expressing and sharing on the AM FB *wall* are also reported by the participants in this study. Surprisingly, other parents have negative perception over status posted by other members concerning the latter's child positive achievement. The chain effect of negative perception is discussed in-depth below, as well as the participants' assumed obstructed freedom of speech, despite having the ability to express anything due to the nature of the Facebook support group where all parents have a child with ASD. Figure 5.5 shows the relationship or effects of negative perception on the participants when communicating in the AM FB group.

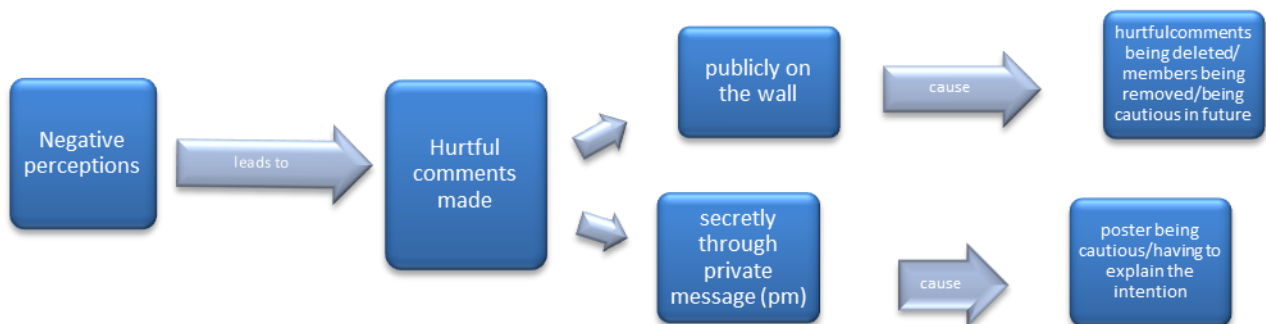
*Negative perceptions*

Figure 5.5. Summary of relationship of negative perception.

### Hurtful comments

Synchronous communication online that adopts written language as a medium poses many challenges. As the non-verbal features such as facial expression, body language and hand gestures are absent, the words being written are easily misunderstood by the readers, or in this context, the members of the Facebook support group. The act of status being misunderstood is described as *Mistaken Intent*, reflecting that the recipient was misunderstood or mischaracterised (Vangelisti, Young, Carpenter-Theune, & Alexander, 2005). This causes others to have negative perceptions of the status being posted on the *wall*, although the content of the status denotes positive vibes.

Getting face-to-face hurtful comments is bound to occur in any interpersonal interaction and this provokes a feeling of emotional injury to its recipients (Folkes, 1982). The same claim can be made for online communication as well. In fact, the effects are amplified as others are able to read the hurtful comments received by the recipients, especially if it is posted in a Facebook group's wall. This could be justified by the study (Kaplan & Berman, 2010) that online social network may have a cognitive and emotional replenishing effects on its users. In the context of this study, the emotional injury due to the hurtful comments, particularly ones publicly made on the *wall*, add to the emotional stress

that the *poster* (parents who posted a status on the AM FB *wall*) already has from managing the child with ASD. How the recipients cope with such emotional injury by being cautious and having to explain themselves are the coping strategies that can be justified by appraisal theory. Appraisal theory advocates that emotions are provoked as the effects of people's valuations of a given event or situation (Lazarus, 1991; Ortony, Clore, & Collins, 1988). The recipients (the parents in this study) have to explain themselves in the same comments thread on the *wall*, for comments made both publicly and secretly, in order to substantiate the misunderstanding that occurs. This explanation usually comes in the form of clarifying the initial intention of the status being posted. This strategy applies to *accepting responsibility* and *problem-solving* as suggested in the eight cognitive and behavioural strategies of appraisal theory (Folkman & Lazarus, 1985). The former refers to one's acknowledgement of his/her accountability in the situation or event while the latter describes deliberate measures to improve the situation or event. The act of explaining oneself is supported by Leary and Springer (2001) who called it assertive reactions by defending oneself with the intention to protect the social relationship and motivate remedial actions. This strategy adopted by the parents in this study shows that they are willing to alter their ego and self-esteem in order to sustain the harmonious social relationship in the AM FB support group.

Having negative perceptions which provoke blurting hurtful comments either on the comment thread or private message could portray the behaviour of the persons. According to Baumeister et al (2003), it seems plausible that "people low in self-esteem are most inclined to boost themselves by means of disparaging and discriminating against members of other groups" (p. 20). These hurtful comments, although they may seem as a way of extending support, perhaps to make others stronger emotionally, actually support the claim that certain types of social support may be perceived as negative 'social strain' and aggravate stress (Cranford, 2004). Instead of alleviating stress by participating in the Facebook support

group, some parents find it to be more depressing due to the added stress given by those members who have low self-esteem. These hurtful comments could also be sparked when parents start to compare other child's achievement to that of their own. This could be supported by the claim that Facebook triggers damaging social comparisons (Chou & Edge, 2012; Haferkamp & Kramer, 2011) which in a way affect the parents' well-being. However, in the context of the AM FB support group, the damaging social comparison through hurtful comments made is minimised when other parents in the group interrupt the comment thread by giving a neutral opinion or the admins gently remind parents to be vigilant with their comments and avoid hurtful comments to others. Hence, parents in the AM FB group have to be mentally and emotionally prepared to receive such unpleasant responses so that it would not stress them further and also not to give hurtful comments to others in return.

### ***Being cautious***

Findings show that the participants in this study adopt the strategy of being cautious in the future for fear of being removed from the group. This is usually done by reserving their comments, not commenting on the status although at times they may have contrasting views towards the status being posted. This strategy is called *Distancing*, which involves detaching oneself from the situation or event (Folkman & Lazarus, 1985). This is further supported by Vangelisti and Young (2000) that people are more likely to simply avoid the person who engages in a pattern of hurtful communication, rather than make deliberate efforts to improve the situation or alter the behaviour of the individuals who start the provocations. This is one of the negative impacts felt by the participants as a result of freedom of expressing and sharing in the AM FB group in which they have to accept other parents' unpleasant behaviours. This strategy of distancing and detaching oneself from the situation or event could be triggered by not wanting to lose face and allowing the feelings to show (Bippus & Young, 2012). The worry of not losing face has driven most Facebook users to display an acceptable self-presentation, which they use to control the impressions



and perception that others may have of them (Leary, 1995). However, this claim does not apply to those parents who openly criticise the participants on the *wall*. Hence, the latter implement the strategy of being cautious when posting a status on the *wall* in future.

### ***Obstructed freedom of speech***

As highlighted in the findings in Chapter 4, although the AM FB group's setting is set as an Open, which supposedly allows anyone to communicate in the group synchronously and asynchronously, some parents feel that they are at times being obstructed from speaking freely. This is caused by the presence of the admins who monitor the communication on the AM FB *wall* to ensure members adhere by the rules and regulations of the group, particularly related to offensive statuses or comments and promoting irrelevant businesses. The notion of the admins' (some call it *moderator*) presence is crucial in avoiding discussion veering on to slippery ground or off topic by disruptive members in the group (Rolland & Parmentier, 2013). Style of communication has a significant effect on online users' satisfaction with the group discussion (van Dolen, Dabholkar, & de Ruyter, 2007), which could influence group motivation and involvement in the discussion (Rolland & Parmentier, 2013). This could justify the admins' role in monitoring the communication as offensive remarks could jeopardise other members and consequently hinder them from participating and posting status/comments on the *wall*. However, from the parents' perspective, the fear of being banned or removed from the group by the admins is perceived as obstructing their freedom of speech, which is the negative effect of expressing and sharing on the *wall*.

Another negative effect reported by the participants in this study due to the expressing and sharing on the AM FB *wall* is the worry of being banned or removed for bringing up sensitive issues. Morgan (1988) claims that sensitive subjects are difficult to be discussed freely in a face-to-face discussion group, as in the context of online discussion group such as in the AM FB group, this claim applies. Sensitive issues, including

vaccination and health supplements, among others, are not encouraged to be discussed on the Facebook *wall*. Thus, this is closely related to the earlier discussion on the parents being cautious before updating any status or commenting on others' status so as not to be banned or removed from the AM FB group. This also discourages the parents' contribution on the AM FB *wall* which brushes off the claim made by Purpura et al. (2011) that individuals who contribute less online fear potential embarrassment due to their failed attempt to change their behaviour. Changing the behaviour in the context of the AM FB support group could refer to the participants' perceptions, behaviours and attitudes on issues relating to ASD. Fear of being embarrassed for having those behaviours, some parents in the group prefer to communicate less on the *wall*. Thus, despite the freedom of expressing and sharing on the AM FB *wall*, the participants feel otherwise due to fear of being banned or removed, which results in them being cautious when communicating.

5.2.3 Research question: c) What competing discourses, if any, animate parents' narrative about their child with ASD, and how do parents mediate such discourses?

### ***Discourse analysis***

The findings in this study show that the participants commonly engage in the narrative discourse. They frequently start the 'conversation' with greetings and phatic talk which are prevalent when writing a status on the AM FB *wall*. This is inconsistent with the previous studies which claim that parents of a child with ASD and also their relatives exhibit deficits in social interaction (Landa et al., 1992; Lindgren, Folstein, Tomblin, & Tager-Flusberg, 2009; Pickles, St Clair, & Conti-Ramsden, 2013; Whitehouse, Coon, Miller, Salisbury, & Bishop, 2010; Wolff et al., 1988) and commonly spurn small talk and are overly formal (pedantic) in their communications (Landa et al., 1992). According to Landa et al (1992), "Abnormal pragmatic behaviours (disinhibited social communication, awkward/inadequate expression, and odd verbal interaction) are also evident in social

conversation due to being influenced by individuals/child with ASD” (p. 251). However, not all of these discourse features are present among the participants in the AM FB support group, probably because it is an online communication compared to the face-to-face communication in the previous studies. Those previous findings contradict the findings in this study as the parents in the AM FB group seem to enjoy small talk which generally involves phatic communication (such as asking for the others’ well-being or simply to start a conversation) or even expressing their feelings of being grateful to be able to find the AM FB support group. Abnormal pragmatic behaviours also do not exist in the AM FB support group, perhaps because the participants have sufficient time to write and edit their ‘conversation’ before posting it to the AM FB *wall*. It might be obvious for synchronous communication between the participants using the private messaging feature but this could not be highlighted as this is beyond the scope of this study. Thus, it could be claimed that the participants in this study involve in a discourse that does not display abnormal pragmatic behaviours but dwell more in phatic and expressive communication as an opening to their narrative discourse.

### ***Narrative discourse***

The narrative has been mentioned previously as a strategy the parents in the AM FB use to tell stories related to their feelings, both positive and negative, the child’s achievements and downfall, family challenges. This is done with the sole purpose of sharing as a way to communicate and seek support from other members of the group. This form of narrative can be categorised as self-disclosure in which they share intimate details and emotions on the AM FB *wall* or private messaging. This can be justified as the participants frequently engage in self-disclosure, which has a therapeutic value that invokes empathetic statements, complemented by gratitude expressions for the support given by other participants (Miller & Gergen, 1998). Although this claim by Miller and Gergen is pertinent to a face-to-face setting, the same can be applied to the online setting. The act of

self-disclosure gives the parents the freedom to choose the content to be shared and viewed by others. The strategy of editing the content of the status before posting it is consistent with the findings in this study that users also think about what to exclude apart from what to include or what to publicise as disclosure is seen as the default because participation and online presence is grounded on it (boyd & Marwick, 2011). It has also been proven that self-disclosure on difficult situations has positive effects on an individual's well-being (Pennebaker, 2003). A neatly written narrative depicting the significant experience of a user on a particular posting can have a great impact on a Facebook page (Glazer, 2012). Thus, this explains why the participants in the AM FB support group use narrative when writing a status on the AM FB *wall* as it gives great impact to its members.

The participants in this study highlight that positive emotions are commonly included in the narratives in the AM FB statuses to celebrate the child's success. Negative emotions are also being expressed in the narrative as these help to develop a more advanced understanding of others' thoughts and feelings (Guajardo & Watson, 2002) and they learn how to negotiate social relationships and manage the parents' own effects (Lagattuta & Wellman, 2002). Laible and Song (2006) claimed that "both emotion-laden discourse and positive affect facilitate the construction of emotional and relational understanding and it seems plausible that emotional and relational understanding is enhanced when emotion is discussed in the context of shared positivity" (p. 207). The AM FB support group prepares this shared positivity context for these parents to exchange the emotion-laden narratives and consequently enhance their emotional and relational understanding among each other. Narrative sense-making often happens in the midst of difficulty, thus helping people to interpersonally cope with hardship by communicating stories of illness (Wittenberg-Lyles, Oliver, Demir, & Baldwin, 2010), stress (Kellas, 2015), and other hardships to others. In the context of this study, stories of struggles, especially when dealing with the child with ASD, are often shared in the AM FB *wall*. The main goals of communication-based

narrative theories include illuminating the ways in which content and process reveal relationships, practices, meanings, and health as they are constructed interpersonally (Braithwaite & Schrod, 2015). This is crucial to ensure a healthy relationship among the members and healthy environment for the online communication to take place. Despite this, the participants highlight the discursive struggles they experience when communicating in the Facebook group. These struggles are very personal and yet are shared through narratives which reveal relationship matters.

### *Discursive struggles*

Discourses, simply put, are ways of talking about the world, and it is through discourse that meaning is created. Meaning is not permanently fixed but rather results from struggles between different discourses. The idea of discursive struggles was first introduced by Baxter and Montgomery (Baxter & Montgomery, 1996) who focused on identifying the dialectical tensions present in a relational talk, specifically the oppositional pairs, connection–autonomy, openness–closedness, and certainty–uncertainty. Although these three-pair concepts are pertinent in discursive struggles, it is expected that a vast array of binary pairs could exist and researchers are encouraged to explore beyond these to suit the context being studied (Baxter & Braithwaite, 2008). Discursive struggles could be easily identifiable, but sometimes the meaning seems to be established that it appears natural and objective (Gleiss, 2015). Nevertheless, the possibility of struggle is still available. Discourse analysis thus entails investigating both discursive struggles and the systems of meanings these struggles provoke (Jørgensen & Phillips, 2002). Findings in this study reveal that the participants experience discursive struggles from the responses given by other members in the ‘Comment’ thread or through private messaging.

The findings in this study reveal the theme of disclosure vs discreet which can be a sub-theme for openness–closedness as it refers to the desire to be open and reveal information versus the desire to be exclusive and private (Baxter & Braithwaite, 2008). In

the context of social media, such as Facebook, the act of disclosing information about oneself depends on the individuals. In the context of the Facebook support group, being disclose aims to let others understand the individual by sharing information and stories (Johnson, 2014), and also reflects the trust that all the members have among each other. The trust that these participants have is so high that they even discuss spousal relationship on the *wall*. Some cultures, including Malay, believe that personal problems should be dealt internally with the partner or family and not discussed in public such as in support groups (Im et al., 2007). The struggle occurs when the participants are criticised for being too ‘open’ for disclosing spousal problems on the *wall*. Although they face this discursive struggle, sharing them means authenticity, showing the individual’s genuine self to the world, and they expect other members to accept that as such (Hellenga, 2012). They view being in a support group means members should have a shared value of supporting each other and being disclose is one way of seeking and obtaining support.

As previously discussed, the participants in the AM FB support group share almost everything related to their personal life. As they are aware of the negative impacts of posting to the AM FB *wall*, they have implemented precautionary steps in order to remain a member of the group and avoid being removed or blocked. This view contradicts that of the study by boyd and Marwick (2011) on teenagers which suggested, “although they accept the public nature of information, which might not have been historically shared (perhaps because it is too mundane), they carefully analyse what shouldn’t be shared” (p. 11). Perhaps this contradiction is due to the samples of the online communities in which the participants in this study are thinking more of the welfare of their child with ASD in comparison to the teenagers who are more concerned of their own self-image. Thus, the participants in this study are more willing to share and disclose all without an act of caution being practised.

Self-help vs helping others could be added to the established theme of the three prominent oppositional pair of discursive struggles. Participation in the online support

groups using Facebook as a platform allows these participants to engage in self-help practices. By reading other members' experience and sharing their own, they gain both informational and emotional support. Helping others, in contrast, may seem to be a discursive struggle for some of these experienced participants as they are willing to take up the role as helpers or assistants for others members' benefit. Similar findings are found in online support groups using e-mails in which messages concerning self-revealing, discussion of personal and emotional issues encourage members to get into "helper role" in which supportive responses to these are twice as frequent as the request for help (Finn, 1999). The satisfaction of individuals with one's support network in computer-mediated contexts is often contingent upon the complicated process of managing their difficult and challenging coping needs while simultaneously attempting to handle delicate relational concerns when seeking support (Kevin et al., 2013). Thus, this explains the discursive struggle of self-help vs. helping others that the participants in this study face when communicating in the AM FB group. While they post a status to seek support for their own challenges, they are inclined to extend support to others as well, especially those who have previously given them support.

These discursive struggles may be seen as the added challenges to these participants who are already facing difficulties managing their child with ASD. Instead of receiving the positive effects of participating in a Facebook support group, they have to deal with these unexpected discursive struggles. Research has claimed that the use of social media may stimulate disinhibited communication (Avery, 1998; Walther, 1996a) and consequently leads to psychological harm to others (Finn, 1999). However, the strategies adopted by the participants in this study in handling discursive struggles may help reduce this psychological harm. Self-explanations in the comment thread and an ignorance of, or refusal to acknowledge the negative comments in the comment thread are two strategies practised by them. These strategies are methods these parents use to mediate differences of experiences among the members in the AM FB group using their dialogic interactions (Innes, 2007).

These methods are crucial to minimise the misinterpretations of the intended meanings among the participants/members to counter the lack of non-verbal features (facial expressions, tone of voice, gestures) in the online support group.

The participants in this study even have strategies for future posting of status to the AM FB *wall* by using politeness and gentle reminders as the opening sentence for their status updates. These strategies, which are put in practice, are social actions which indicate that these parents can “diffuse even high tension situations comfortably and still foster open dialogue” (van Leeuwen, 2009, p. 156). However, this open dialogue is governed by the politeness and gentle reminders set by the parents to minimise the high-tension situations. Again, the parents’ action and reactions, which van Leeuwen (2009) termed as “*distillation* (a quality distilled from the given context of ‘getting support’) is a stage where parents build appropriate rapport, uses diplomacy and tact, and eliminate roadblocks” (p. 157) in order to organize and negotiate relational contradictions (Richard & Turner, 2010) occurring on the AM FB *wall*. A similar notion is shared by (Duthler, 2006) in which politeness and expressions such as the admission of impingement are strategies used by social media users to create acceptable and pleasing impressions to other members as practised by the parents in this study. Therefore, these findings on narrative discourse suggest that despite the benefits of support these parents obtain through active participation in the AM FB support group, discursive struggles of ‘disclosure vs discretion’ and ‘self-help vs helping others’ are unavoidable. The participants have used appropriate and wise strategies in alleviating the negative impacts of these discursive struggles in order to maintain a healthy relationship with other members and ensure the sustainability of the Facebook support group.

### **5.3 Conclusion**

This chapter has provided an extensive discussion of the research results and findings in relation to the research objectives and questions raised in this study. The theories emerged



from the three data analysis stages are examined and compared with the theories reviewed in the relevant and pertinent literature. This chapter reveals the significant use of Facebook as a tool for communicating support for this particular Facebook page called Autisme Malaysia. Positive impacts surpassed the negative impacts for these parents of a child with ASD when communicating in the AM FB group. Both synchronous and asynchronous communicative features offered by Facebook are utilised by the participants in order to communicate support for the benefits of their child and their own selves too. Although there are challenges communicating in the AM FB group, the participants stay positive and implement precaution strategies when posting on the *wall* in future.

The following chapter is the conclusion of the thesis. It gives a brief account of the researcher's reflection on her experience conducting this study. This is followed by an overall discussion of the most significant research results and findings. The significance and implications of the study are also presented. Limitations of the study are highlighted as well and most importantly, recommendation for future research are emphasised to overcome these limitations.

## **CHAPTER 6: CONCLUSION**

### **6.0 Introduction**

As the conclusion of the thesis, this chapter provides an overview and reflection of the whole research experience. It summarises the researcher's whole experience in conducting this study. The chapter gives an overall discussion of the research results and findings that are highly significant based on the research objective and research questions. The significance of the research is also highlighted with relevance to Facebook, social support groups and ASD. The implications of this study to parents of a child with ASD, support workers, and social network researchers, among others, are also discussed. Lastly, recommendations are given based on the results and findings of this study and the possible directions and aspects that can be investigated in future studies.

### **6.1 Researcher's reflection on the research experience**

This study was conducted as a part of the Doctoral Degree requirements. The motivation to undertake this study was derived from the researcher's own curiosity of finding out what could explain the condition of her late brother who in 1970's was 'labelled' as having mental disorder, and yet he was physically fine and could take care of his daily chores on his own. His only imperfection was that he was a slow learner; he could only utter a few words when he was a child and hardly any sentence was articulated. He could copy writings and even imitate words taught by the researcher when he was in his teenage years. His behaviour made the researcher even more confident that her brother did not have a mental disorder and most probably he was having delayed speech or ASD. That had led the researcher to participate in a support group for parents of a child with ASD to obtain more information and to ratify her perception of her brother's condition. Autisme Malaysia

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Facebook page appeared when the online search was carried out on the support group for ASD in Malaysia. This attracted the researcher to join the Facebook group as a member and later to conduct research on the group.

The study was conducted on Autisme Malaysia Facebook group which was set up as a support group offering support for parents of a child with ASD in Malaysia. This qualitative study involved the twelve participants who were members of the Facebook group and who were recruited through the Facebook group. A small part of quantitative data was collected through the participant observation and recorded and analysed using Microsoft Excel. The quantitative data showed the frequency of statuses and comments made by the participants which indicated the high/low engagement with the Facebook group. It was also used to design the questions for the semi-structured interviews. The qualitative data was gathered through archived Facebook data and semi-structured interviews which were then analysed using the NVivo software. The data analysis allowed for data triangulation to investigate the entire spectrum of the parents' experiences in using Autisme Malaysia Facebook group. The results and findings were presented based on the proposed methodology while the discussion of findings was structured based on the research objectives and research questions. These findings helped the researcher to highlight the significance and implication of the study, the limitations and also recommendations for future research.

One of the biggest challenges of conducting this study was to get the ethics approval from the Tasmania Social Sciences Human Research Ethics Committee. As Facebook was considered a new area of research, particularly in the University of Tasmania, it took almost three months for the application to be reviewed, revised and approved. The nature of this study which involved social media and parents of a child with ASD, which was considered as the high-risk group, had made the application of ethics approval to be quite rigid. The issue of privacy, ownership of the Facebook data, and consent of the participants contributed

to the delayed approval of this study. Another challenge faced by the researcher was some of the initial participants who had given consent to participate in this study (through private messaging on Facebook) could not be contacted for interviews. Not all private messages were replied to, and this had forced the researcher to once again recruit participants. This had taken more time than what was planned at the beginning of this study. However, these two challenges were successfully taken care of and this had made the researcher become more experienced to manage similar difficulties in future.

## **6.2 Overall discussion of the research results and findings**

This research has discovered three major findings which are interconnected to each other and lead to positive and negative impacts on the participants in this study. The impacts are the cause and effect of the discursive struggles they experience when communicating in the AM FB group. This section provides a brief discussion of the results and findings and the most significant findings are presented.

### **6.2.1 Online engagement**

Online engagement in the context of Autisme Malaysia Facebook involves more than merely sitting in front of the computer, logging in, updating a status and posting comments, and reading others' statuses on the Facebook *wall*. Motivation to join and communicate on the AM FB *wall*, in turn, become the motivating factor for other parents to do the same. These are the factors that constitute the online engagement for the participants in this study. The trust these participants have in the group and its members encourage them to engage with the group and this can be seen from the frequency of activities conducted on the AM FB *wall*. The postings of status, comments, visuals and video every day are overwhelming as the responses given by the members are very encouraging. The responses

in the form of social support exchanges make the participants willing to share the challenges they experience, even very personal issues, with others on the AM FB *wall*. These participants become more profoundly motivated to engage highly with the group as they face similar challenges as other members. This is done through asynchronous and synchronous communication offered by Facebook. Thus, these factors constitute online engagement for these participants as this later leads to them feeling the sense of belonging and bonding with the group, to the point that they regard its members as their family.

### **6.2.2 Social support exchanges**

Social support exchanges are evident as the participants become involved in seeking, obtaining and offering support in the AM FB group. Informational, emotional and religious support are the three most common types of social support being exchanged on the *wall* and through private messages. Previous online support groups utilise different platforms such as e-mails (allow only asynchronous communication) and bulletin boards/chat rooms (allow only synchronous communication), but Facebook offers both asynchronous and synchronous communication to occur simultaneously. Hence, the participants in this study utilise both communicative features to exchange social support. What makes these exchanges significant in the context of the Facebook group is the 'Like' button in which clicking on it is an indication of offering support. The participants in this study reveal that the number of 'Likes' on their status is a powerful indication of members providing support to them. Realising this paralinguistic feature as a means of offering support, the participants, in return, do the same to others' status. What makes this finding valuable is that the parents would click on the 'Like' button based on the content of the status rather than the person posting it. It indicates that it does not matter whether they know each other personally or not, they would click it in order to offer social support as most members realised the importance of the 'Like'. Thus, it

can be suggested that the Autisme Malaysia Facebook support group has achieved its aim and purpose in offering social support for parents of a child with ASD in Malaysia.

### **6.2.3 Negative impacts**

One surprising finding in this study is the occurrence of negative experiences whilst participating in the AM support group. To get hurtful comments from others, who have a negative perception of the status being posted on the *wall*, is potentially distressing, especially when these parents are already facing emotional stress due to managing the child with ASD. The negative perception later leads to hurtful comments being made. The hurtful comments, frequently sent through private messaging and occasionally on the AM FB *wall*, are damaging to these participants. Ironically the negative perception is ignited from status sharing about the child's positive improvements which should be supported and celebrated by other members. Yet, there are members who perceive some parents as being arrogant and 'showing off' and this apparently leads to hurtful comments.

### **6.2.4 Transition as a significant experience**

The transition is a significant experience which the participants in this study go through when joining and communicating in the AM FB group. The transition can be seen when their role changes from being *lurkers* when first joining the group to active participants after being in the group for a period of time. Another transition is their negative perspective on their life of having a child with ASD at the beginning when joining the group changes to positive due to the supports obtained from the group members. This shift is motivated by the urge to learn more about ASD and to possibly unofficially 'diagnose' their own child, or confirm their concerns about their child. Exchanging support on the *wall* and clicking on the 'Like' button are indications of how these parents shift their role from

*lurkers* to active participants/communicators. The parents' increased participation often has an effect on motivating other parents to join the AM FB group. Most parents are encouraged to communicate actively on the *wall* after realising that the information and experiences shared are indeed valuable and beneficial both for the parents and their child.

Transition in the context of the AM FB group can be seen when these parents change the mode of communication either from synchronous to asynchronous, or vice-versa. Some start communicating through private messaging, commonly seeking informational support, to members whom they have identified are resourceful through their reading of the latter's postings on the *wall*. This later gives these parents a boost of self-esteem to consequently shift the communication to the AM FB *wall* as they could see the positive effect of sharing things on the *wall* rather than private messaging. On the other hand, some parents communicate by posting on the *wall* before shifting to sending private messages to those members whom they believe could offer specific social support. This extension of support through private messages results in these parents being more likely to build networking ties and create close bonds with other members.

The effect of building networking with other members in the group, both online and offline, is another transition these parents experience. This networking built online could be seen when the parents are able to *tag* the name of other members who could provide informational assistance particularly to those seeking the support. The names being tagged are commonly those parents who have become members of the AM FB group for three years or more and it involves seeking informational support such as getting the child proper diagnosis, finding therapy centre and appropriate school, enrolling the child into school, and extending therapy activities at home. Networking built offline, in contrast, refers to the parents engaging with each other, particularly those coming from the same geographical location, outside of the virtual world. As they reside within the same district or state, these parents have the opportunity to hold face-to-face meetings and conduct social activities for

their child with ASD. Consequently, this could further enhance the support both for the parents and the child.

The most significant transition experienced by these parents in the AM FB group is the shift from negative to more positive outlook related to their own selves and their child as well. The parents initially are in denial, refusing to accept that their child has ASD. This can be seen from the sharing of negative feelings, feeling lost and guilty, and helpless on the FB *wall*. This, in turn, changes as the parents get more of the support that they need through exchanges of support from other members in the group. Consequently, they share more positive postings related to their child's improvement, their own positive changes such as their determination in helping their child, and their planning for future undertakings for their child with ASD. Although these parents face discursive struggles due to this sharing of positive postings, that does not deter them from continuing sharing and communicating on the AM FB *wall*. As a precaution for avoiding negative perceptions from other members, these parents implement certain strategies. When posting positive statuses, they would be very careful with their language use. The word choice is very pivotal for them as they would not want the status to offend other parents in the group. They regularly check and edit their writing before posting it on the AM FB *wall*. Hence, this alleviates the possibility of offending others and they could continue sharing positive statuses.

### **6.3 Significance of the research**

On the methodological level, this research combines multiple data collection and data analysis techniques as an innovative approach to the existing methodology, and content analysis commonly adopted in previous research on Facebook. The use of this blended netnography approach allows greater insight and in-depth understanding of the experiences of using Facebook among the parents of a child with ASD in the Malaysian context. Using grounded theory analysis to analyse data is also substantial to obtain further understanding



of the pre-empted and emerging themes which are inter-related to one another. This methodological approach contributes to the past approaches that may have been using content analysis as the common approach when researching Facebook.

This study has opened up the benefits that Facebook could offer as a tool of communication. The myriad of social media in the online world today could provide potential benefits when they are used correctly and wisely. This is proven by the Autisme Malaysia Facebook group which has become the best platform for exchanging social supports among these parents of a child with ASD in Malaysia. Both asynchronous and synchronous communicative features allow the social support exchanges to occur which result in positive impacts for both the parents and their child. This also proves that Facebook is not all negative and damaging to its users.

This study demonstrates that Facebook could be an agent of social change, particularly in the context of the parents of a child with ASD in the Malaysian context. The parents' perception and attitude towards the child could be improved when they are highly engaged with the Facebook group. This results in not only the changes in the parents personally but also impacts the child positively. This is evident when the parents have more positive outlook on how to manage the child and lead them to give the best to the child particularly matters related to therapies and education. This, in turn, impacts the child positively as he/she receives the appropriate assistance that could help the child in future. It shows that Facebook can be an effective agent of change when its users or members of the Facebook group play their role according to the Facebook's terms and Facebook group's rules. When the members adhere by the rules, the impacts are so encouraging that parents are willing to share even the most personal matter on the Facebook group's *wall*. Hence, this indicates the trust members could possess on the Facebook group.

On the theoretical aspect, this study could contribute to the existing body of knowledge related to the use of online support groups which previously utilised the use of e-

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mails, bulletin boards and chat rooms. Facebook as a platform for this purpose has been illustrated by the researcher on the ways in which the features, linguistics and paralinguistics allow for social support to be exchanged between the users in the specific Facebook group. The setting of the group's privacy could be altered to suit the needs and purposes of the group. In the context of the AM FB group, making it a Public Group enables it to reach out to those Facebook users, who are not members of the group, to increase awareness of what ASD is. In turn, this perhaps could alleviate the common social stigma associated with the child with ASD and their family, and then lead to them being accepted by the general public.

Another contribution of the findings in this study is they add to the theoretical aspect of using online support groups among the parents of a child with ASD. As previously highlighted in the literature review, most studies in this areas have been conducted in the Western setting with minimal research conducted in an Asian setting involving countries such as Japan, Korea and Taiwan. To date, very few studies on this topic have been carried out in South East Asia, particularly Malaysia. Although the findings are specific to the Autisme Malaysia Facebook support group, they may be applicable to other settings as the prevalence of having a child with ASD is common across countries worldwide, regardless of where the child is within the ASD spectrum.

Finally, this study highlights the importance of this Facebook group as it is described as the best and the only platform available online for these parents of a child with ASD in the Malaysian context. The scarcity of information and support offline from the governmental and non-governmental agencies in Malaysia has forced these parents to find other sources related to ASD. Only by joining and communicating in the Autisme Malaysia Facebook group are they able to gain the much-sought support needed for the sake of their child with ASD. Ironically, this Facebook group has taken over the responsibility of providing support which is supposedly provided by those two agencies. Thus, these significant findings, taken together, prove that this study has contributed to the body of

knowledge relevant to Facebook, online support group, social support and the parents of a child with ASD in Malaysia.

### **6.4 Implications of the research**

This section provides the implications of this study to various stakeholders including the parents of a child with ASD, medical staffs and teachers, and social network researchers.

- The adoption of Facebook group to complement face-to-face support groups

This study suggests that Facebook could be adopted as a tool of communication to complement existing face-to-face support groups, if any. As 19 million Malaysians are now users of Facebook, it is plausible to adopt it as a means of reaching out to those parents of a child with ASD in Malaysia. As highlighted in this study, the near non-existence of face-to-face support group for these parents could be resolved by having a Facebook group. This is because Facebook becomes the only platform these parents seek and gain support vital to their own well-being and as well as their child with ASD. Hence, similar use of Facebook can be extended to cater to other online support groups, particularly stigmatised groups.

- Connecting parents who are disadvantaged geographically

Facebook is an influential communication tool which could connect parents of a child with ASD wherever they are in Malaysia. Although there is a debate that those in the rural areas are at a disadvantage due to limited access to the internet, it can be disputed as most of the rural areas in Malaysia now have internet access. Having a Facebook support group is indeed a blessing for these parents in the rural areas as they are able to learn from other parents, for example, therapies which they could try to implement with their child at home. This could alleviate the cost of travelling to the therapy centres which are usually situated in the urban areas.

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- Inviting health professionals and educators to Facebook group

As this study highlights the wealth of benefits of a Facebook support group, specifically to the parents of a child with ASD in Malaysia, it is pivotal to include other related people into the group. Health professionals such as paediatricians, speech therapist and occupational therapist, and also educators should be invited into the group to enable them to understand the predicament of these parents. It can also become the means of reaching out to these parents so that support could be offered, for example, therapists can offer advice based on their expertise, to parents who may not be able to afford sending their children for therapy. In light of Facebook as the most popular social networking site, online health community is growing exponentially (Campbell, 2008). Therefore, the presence of those people in the group could contribute to more 'expert' social support.

- Facebook as a field for research

This study contributes to the growing interest of using Facebook for research purposes for the social media researchers. Initially, Facebook was frequently used only for recruitment of participants for research in which the research had no relevance to Facebook. Subsequently, there was a growing interest in conducting research on Facebook in the area of business, marketing, branding and celebrity fan pages. This interest then expanded into support groups involving patients with medical illness such as cancer and diabetes. The samples in these Facebook research ranged from patients, carers, students and Facebook users in general. Hence, this shows that Facebook has become an emerging field of research as it could cater to different disciplines which require different sampling and specific geographical locations or worldwide.

### **6.5 Limitations of the research and recommendations for future studies**

There are several limitations to this study. The first limitation is the number of samples and the homogenous sampling. Although these twelve samples provided sufficient

data to the extent that it becomes saturated and the number is suitable within the time frame of this study, future research could recruit more participants for a longitudinal study to explore if it produces similar findings. It could also include participants from various ethnic background rather than homogenous as in this study, which involves only Malay.

Second, this study only investigates the frequency of 'Like' button clicked by the participants. Future research could investigate extensively on the type of content that generated the most 'Like' in a Facebook support group. This will indicate the behaviour of the users in providing support through the paralinguistic feature on Facebook. In the final stage of conducting this study, Facebook has introduced other 'Reactions' buttons apart from the existing 'Like'. 'Reactions' buttons including love, happy, sad, and angry are added to cater to the needs that the 'Like' button does not meet. Status containing sad news, such as death, would not be suitable to be given 'Like' and thus encourages Facebook operator to add these new 'Reactions' button. Future research could investigate the use of these 'Reactions' buttons to discover if they are also intended as a show of support to members in a Facebook support group.

In this study, the content of the status posted on the AM FB *wall* is analysed based on themes. The pre-empted and emerging themes indicate what is being communicated by the participants in this study. Future research could examine the words used in the status to determine the frequently used words which are prominent in an online support group discourse. It has been highlighted that there are limited studies conducted on Facebook discourse unlike its counterpart, the printed media. The choice of words used in Facebook status could predict the users' personality and how they affect the responses given by other members in the 'Comment' thread. The comments, either positive or negative, could perhaps be determined by the choice of words used by the posters.

Another limitation of this study is that the textual content of the status is the only archived Facebook data being investigated. As some statuses comprise visuals and video

recordings that accompany the text, it is worth finding out for future studies how these non-textual data enhance the text. The non-textual data may also be an influential factor for members to offer social support as this multi-modality discourse enriches the users' experience in using Facebook as a support group. Another aspect to be explored is to count the number of comments given to a status to indicate which content generates the most responses. This could also be used to predict the behaviour of the members of the group.

This study has highlighted the transition of the participants from *lurkers* to active participants or communicators or also known as posters. The 'voice' of *lurkers* is not commonly heard in comparison to posters, although they are the largest group of Facebook users. Although *lurkers*, unlike posters, leave no trace, studying their role particularly in the Facebook support group may be worthwhile for future research as they could also be 'active' participants. Reading, listening, being receptive, liking, connecting, and forwarding are activities conducted on Facebook, which is in fact forms of communication vital to Facebook research, especially support group as members learn so much just by reading others' experiences on the *wall*.

Substantial ethical considerations are highlighted when proposing this study. The most common issue concerning the nature of data collection in social media, specifically Facebook, is contentious. While Facebook allows for more data to be collected and archived in a much easier way, the ethical nature of such an approach is still questionable. Is it ethical to collect data from the *Public Group* without the authors' explicit consent? Who owns the authority of the comments made by others on the posters' status since the latter could easily delete comments which are unpleasant? Do the posters still own what has been posted to the FB *wall* or can Facebook claim its ownership? These are the debatable aspects that can be investigated further in future research which could enlighten and guide the Human Research Ethics Committee in approving ethics application concerning research on Facebook.

## **6.6 Conclusion**

Over the past decade, social networking sites and electronic communication have irrevocably altered the way in which people communicate. Whilst our modes or ways of communicating have changed, our basic human needs to both seek and provide support have not. Due to the various challenges and struggles in life, people would seek social support in different ways. Hopefully, this study has enlightened us to realise that the ups and downs going through the journey of life would compel us to search for avenues to seek social support and Facebook has the possibility of providing the platform.

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**Appendix 1: Ethics approval**

Social Science Ethics Officer  
Private Bag 01 Hobart  
Tasmania 7001 Australia  
Tel: (03) 6226 2763  
Fax: (03) 6226 7148  
Katherine.Shaw@utas.edu.au



HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

02 September 2014

Dr Megan Short  
Education  
Private Bag 1307

Dear Dr Short

Re: FULL ETHICS APPLICATION APPROVAL

Ethics Ref: H0014173 - The use of Facebook as a tool for a support group among parents of children with Autism Spectrum Disorder (ASD) in Malaysia

We are pleased to advise that the Tasmania Social Sciences Human Research Ethics Committee approved the above project on 31 August 2014.

This approval constitutes ethical clearance by the Tasmania Social Sciences Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approval of other bodies or authorities is required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.
2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au).

A PARTNERSHIP PROGRAM IN CONJUNCTION WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

**Appendix 2: Approval to conduct study on the AM FB group by the admin**

Private Bag  
1307 Launceston  
Tasmania 7250 Australia  
Phone (03) 6324 3265  
Fax (03) 6324 3048  
Email [www.utas.edu.au](http://www.utas.edu.au)



FACULTY OF EDUCATION- UNIVERSITY OF TASMANIA

Date : 28 April 2014

Dear Encik Zamri Tembol,

Seeking approval to conduct a study on Autism Malaysia (AM) Facebook (FB) page

The PhD candidate, Hema Rosheny Mustafa, ID No: 184593, of the Faculty of Education, University of Tasmania, is seeking approval from you to conduct a study on Autism Malaysia Facebook support group page.

This study will investigate the communication among parents of autistic children in the AM FB page.

Proper consent will be obtained from parents who volunteer to become participants and ethics will be respected and met during the conduct of the study.

No assistance is expected from the admin during the conduct of the study.

Regards,

(HEMA ROSHENY MUSTAFA)  
PhD Candidate

*Request approved.*

(MEGAN SHORT)  
Main Supervisor

*28/4/2014*

(FRANCES FAN)



Private Bag 1307 Launceston

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FACULTY OF EDUCATION – UNIVERSITY OF TASMANIA

INFORMATION SHEET FOR PARENTS

**The use of Facebook as a tool for support group among parents of Autism Spectrum Disorder (ASD) children in Malaysia**

**Invitation**

You are invited to take part in a PhD research project exploring the use of Facebook as tool for support group among parents of Autism Spectrum Disorder (ASD) children in Malaysia. This research is being conducted by Mrs Hema Rosheny Mustafa in the Faculty of Education, University of Tasmania. This study is being conducted in partial fulfillment of a PhD study under the supervision of Dr. Megan Short (Chief Investigator) and Dr. Frances Si Fan. Mrs. Hema is also a lecturer in University of Technology, Malaysia (UTM).

**What is the purpose of this study?**

The main purpose of this study is to explore the use of Facebook as a tool for support group among parents of ASD children in Malaysia. It will explore how Facebook page (Autisme Malaysia) is used by parents in seeking and obtaining support and how it influences parents' decision in choosing the type of education for their child.

**Why have I been invited to participate?**

You have been invited because you are a member of Autisme Malaysia (AM) Facebook page.

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

Prior to this, you have been invited through AM Facebook page in which you have agreed to become a participant. Your involvement is voluntary and there is no consequence if you decide not to participate.

### **What will I be asked to do?**

If you agree to participate, you are giving the researcher permission to use the postings that you had done in AM Facebook page for a period of three months. This includes texts, photos and links. If you feel that there is any posting that you are not comfortable to be included in the study, you can inform the researcher.

Participating in the study requires a face-to-face interview. You will be asked on your experience of using AM Facebook page which includes how and why you use it. The interview will be 30 minutes and the time and place will be decided by the participant. The interview will be audio recorded and you have the chance to review and correct the transcript.

All information and quotes will be given pseudonyms.

### **Are there any possible benefits from participation in this study?**

By participating and sharing your experience in using AM Facebook page, it will give an insight on the prospective usage of Facebook as a tool for support group. Your activities and communication on AM FB page could be valuable in giving and obtaining support among members of AM FB page. Hopefully your participation will shed light on the advantages and disadvantages of using Facebook for support.

### **Are there any possible risks from participation in this study?**

Although you may be sharing personal things (related to your ASD child) for this study, you can always inform if you wish not to include certain postings especially in the AM Facebook page. This study is basically looking into your experience of using AM Facebook page as a tool for support group. The interview will be conducted in a friendly atmosphere and the list of questions will be given prior to the interview. The questions could probably upset you and if you feel uncomfortable during the interview, you may withdraw from the interview without giving any explanation.

**What if I change my mind during or after the study?**

If at any time you change your mind and decide to withdraw, you can do so by informing the researcher without providing an explanation. You can withdraw at any time within 14 days of giving consent or interviewing without any consequence. However, if you change your mind after 14 days, it is not possible to remove your data from the study as the research will be published by February 2015.

**What will happen to the information when this study is over?**

The data will be electronically and physically kept for 5 years from the date of first publication. The data will be archived and used for other projects with permission from you or otherwise securely destroyed.

Your data will be treated in a highly confidential manner as pseudonyms are used to ensure your data is unidentifiable by others.

**How will the results of the study be published?**

A thesis will be written, published and stored at the University of Tasmania, Australia and University of Technology Malaysia, Malaysia at the end of the study. The results and findings of the study may also be published in academic journals.

If you wish to be identified or not identified in the publication of the results, please inform the researcher.

**1. What if I have questions about this study?**

If you have any question, please contact the Student Investigator, Hema Rosheny Mustafa at [Hema.Mustafa@utas.edu.au](mailto:Hema.Mustafa@utas.edu.au)

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on +61 3 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [H0014173].

Consent is implied by signing the written consent form.

Thank you for reading this information and your assistance with this study.

**Appendix 4: Consent form for participants**

Private Bag 1307 Launceston

Tasmania 7250 Australia

Phone (03) 6324 3265 Fax (03) 6324 3048

Email [www.utas.edu.au](http://www.utas.edu.au)



FACULTY OF EDUCATION – UNIVERSITY OF TASMANIA

**CONSENT FORM – FOR PARTICIPANT**

The use of Facebook as a tool for a support group among parents of Autism Spectrum Disorder (ASD) children in Malaysia

1. I agree to take part in the research study named above.
2. I have read and understood the Information Sheet for this study.
3. The nature and possible effects of the study have been explained to me.
4. I understand that the study involves the use of (i) my postings to Autisme Malaysia Facebook page, which include texts, photos and links, and (ii) my activities done on Autisme Malaysia Facebook page, which include 'Like', 'Comment' and 'Share'. My postings will be retained as part of this research, even if I choose to delete the postings or my Facebook account.
5. I will participate in an interview of approximately 30 minutes which will seek my experience in using Autisme Malaysia Facebook page. The semi-structured interview will be audio taped with my permission and I have the opportunity to review the transcript if I require. I will be able to correct the transcript of the interview.

Contact No: \_\_\_\_\_

6. I understand that participation involves the risk(s) that I would be uncomfortable during the interview. However, I have the right to withdraw from the interview without giving any explanation.
7. I understand that the data will be securely kept in a password-protected UTAS laptop and collaborative file storage solution on the Microsoft SharePoint Suite when the researcher is in Malaysia and all hard copy of data and printed documents research data will be securely stored

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

in a locked cabinet of the Chief Investigator's office in the Faculty of Education in University of Tasmania for five years from the publication of the study results, and will then be destroyed unless I give permission for my data to be stored in an archive.

8. Any questions that I have asked have been answered to my satisfaction.
9. I understand that the researcher(s) will maintain confidentiality and that any information I supply to the researcher(s) will be used only for the purposes of the research.
10. I understand that the results of the study will be published and I will be identified as a participant in the publication of the study results.
11. I understand that my participation is voluntary and that I may withdraw at any time without any effect of signing this consent form.

Participant's name: \_\_\_\_\_

Participant's signature: \_\_\_\_\_

Date: \_\_\_\_\_

### Statement by Investigator

☒

I have explained the project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐

The participant has received the Information Sheet where my details have been provided so participants have had the opportunity to contact me prior to consenting to participate in this project.

Investigator's name: HEMA ROSHENY MUSTAFA

Investigator's signature: Rosheny

Date: 7 Oct 2014

## Appendix 5: Semi-structured interview questions for participants

### Interview Questions

#### *Soalan temubual*

Below are the questions to be discussed during the interview session. The interview will take approximately 30 minutes of your time.

Soalan-soalan dibawah akan dibincangkan ketika sesi temubual. Temubual tersebut akan mengambil masa lebih kurang 30 minit.

1. Could you share some brief information about yourself and your child?  
*1. Boleh anda berkongsi sedikit informasi mengenai diri anda dan anak anda?*
2. Could you share the whole experience in using Autisme Malaysia Facebook support group? *(When do you become a member? What motivates you to join? Do you consider yourself an active member? How often do you log in and participate in the discussion in Autisme Malaysia Facebook? etc)*  
*2. Boleh anda kongsi pengalaman menggunakan Facebook Autisme Malaysia? (Bila anda menjadi ahli? Apa yang mendorong anda untuk melibatkan diri? Adakah anda ahli yang aktif? Sekerap mana anda 'log in' dan menyertai perbincangan didalam Facebook Autisme Malaysia? Lain-lain)*
3. How do you feel joining the Autisme Malaysia Facebook support group and participating in the discussion? What are the advantages/benefits and disadvantages/challenges of joining the group and participating in the discussion?  
*3. Apakah perasaan anda menyertai Facebook Autisme Malaysia dan melibatkan diri dalam perbincangan? Apakah kelebihan/keistimewaan dan kekurangan/cabaran yang anda hadapi ketika menyertai dan melibatk diri dalam perbincangan?*
4. To what extent participating in the Autisme Malaysia Facebook support group helps in managing your child with Autism Spectrum Disorder (ASD); diagnosis, treatment, education, parenting, etc?

## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

4. *Sejauh mana penglibatan dalam Facebook Autisme Malaysia membantu anda untuk menguruskan anak istimewa anda; diagnosis, rawatan, pendidikan, keibubapaan, dan lain-lain?*
5. Is there anything that you would change on Autisme Malaysia Facebook support group?  
*Adakah apa-apa yang ingin anda ubah pada Facebook Autisme Malaysia?*

Thank you for your cooperation and precious time.

*Terima kasih untuk kerjasama dan masa anda yang berharga.*

## Appendix 6: Participants' observation sheet

Participants Observation Sheets									
Month	Week	Participant	Postings Categories/ Frequency					Share	Descriptions
			Texts	Photos	Video	Likes	Comment		
Jul-14	1	Participant 001				I	II		tagging name
	3				I	III	III		Que as a comment, Suggestions & reasonings, video posted w/o text, giving encouragement
	4					I	I		giving encouragement
Aug-14	1		I			I	I		Text with photo & tagging name, comment on own status
	2		I			II	II		Text with photo , comment on own status, tagging name, giving encouragement
	3		I			IIII	IIII		religious support + encouragement, informational support, text with photo, comment on own status, expressing wishes
	4		II	III	I	IIII III	IIII III		Birthday wishes, photo w/o text, experience shared, expressing gratitude, answering queries
Sep-14	1					IIII	IIII		Expressing humour, Expressing gratitude, giving clarification
	2					I	I		Giving encouragement,
	3					III	III		Expressing wishes, giving compliments, expressing sadness,
	4					III	III		Expressing gratitude, expressing wishes, giving suggestions,



## FACEBOOK FOR PARENTS OF A CHILD WITH ASD

Jul-14	1	Participant 002				IIII	II		tagging name, giving suggestion
	2					IIII IIII	II		asking que, name tagged, expressing disappointment & hope
	3					IIII IIII	II		asking que,
	4					IIII IIIII	IIII		sharing experiences, emotional support, expressing disappointment, reasoning & suggestions
Aug-14	1					IIII	II		expressing wishes, sharing experiences
	2					IIII IIIII	IIII		Giving suggestion, tagging name, religious support, sharing experiences, expressing gratitude
	3		I (narrative of child with ASD behaviour with typical-developing sibling	I		IIII IIIII	IIII IIII		Giving assurance, expressing gratitude, giving suggestions, emotional support, expressing wishes
	4		I (announcing newborn)			IIII IIIII	IIII		Asking que, sharing experiences, giving suggestions
Sep-14	1					IIII	IIII		Giving suggestions; giving emotional support
	2		I (sharing child's behavior at home)	I		IIII	II		Sharing similar experiences; Giving compliments
	3					IIII	IIII		Giving suggestions; giving encouragement;
	4		I (narrative of child's behaviour)	I		IIII II	IIII		Expressing wishes, sharing similar experiences

Jul-14	1	Participant 003	I (sharing hobby)	I		II	II		Giving clarifications, sharing links,
	2		II (sharing hobby; narrative of child's social activity)	II		II	II		Giving clarifications & suggestions, commenting own status,
	3		I (narrative of child's behaviour)			II	I		Giving clarifications & sharing experiences
	4		I (narrative of child's behaviour)						
Aug-14	1		II (narrative of child's behaviour)	II		II	II		Sharing experiences, asking que, tagging name
	2		II (expressing gratitude; making announcement;	I		IIII	IIII	I	Giving suggestions; expressing happiness
	3			II					
	4					I	I		Expressing excitement;
Sep-14	1		I (Seeking opinion;			IIII	IIII		Expressing happiness, expressing humour, expressing disappointment, sharing other's experiences,
	2		II (Sharing child's social activities;	II		IIII	IIII	III (sharing other's post, sharing older posts)	Sharing similar experiences, giving compliments, sharing photos and expressing jokes, expressing hopes,
	3		II (Sharing old post, seeking informational support,	I		IIII	IIII		Giving encouragement, seeking clarification,
	4		II (Giving opinion, sharing parenting skills)	I		II	IIII II		Giving assurance + encouragement, expressing humour, giving informational support, giving emotional support + religious support, expressing wishes,

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Jul-14	1	Participant 004	I (narrative of child's behaviour)	I		IIII III	IIII	sharing (similar) experiences, giving suggestions, informational support,
	2					IIII II	IIII	sharing similar experiences (suggestions + information); asking for clarification + name tagging; giving suggestions;
	3		I (narrating conversation with child's teacher + expressing disappointment)	I		III	I	Expressing gratitude + name tagging;
	4		II (Sharing experiences; expressing gratitude)			IIII III	IIII IIII II	Giving suggestions; expressing prayer; Giving opinion; Giving compliments; giving clarification; sharing similar experience; expressing wishes; expressing gratitude; giving encouragement;
Aug-14	1		I (sharing narrative on emotional event with child)			IIII IIII	IIII	sharing similar experience; expressing wishes; expressing gratitude; giving encouragement;
	2					IIII II	IIII	Sharing experience; expressing disappointment; expressing excitement; giving compliment
	3		I (narrative of child's behaviour)			IIII	III	Sharing experience & tagging name; giving emotional support;
	4					IIII	III	Giving clarification; informational support; sharing link;
Sep-14	1		II (Sharing experiences; expressing gratitude)			IIII III	IIII I	Expressing excitement & disappointment; giving compliment; asking clarification & expressing gratitude; giving suggestion;
	2		II (narrative of child's behaviour)			IIII II	III	Sharing experience & tagging name; giving emotional support;
	3					IIII IIII	IIII IIII	Giving suggestion, tagging name, religious support, sharing experiences, expressing gratitude
	4					IIII	IIII	Giving clarification & expressing gratitude; giving complimen

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Jul-14	1	Participant 005				IIII II	II		Expressing wishes; sharing similar experiences & giving suggestions;
	2		IIII (making announcement; pic of son without any caption; Sharing own blog; Sharing achievement of NGO related to ASD; Informational support & tagging others;)	III		IIII	IIII IIIII		Informational support; Tagging others; answering queries; Expressing wishes; Smiley icon; Giving opinion; expressing hope & self-motivation;
	3					III	IIII		Expressing wishes; Informational support; Expressing gratitude; Giving emotional support;
	4		IIII (Updating group profile pic; Exp	IIII		IIII IIIII	IIII IIIII		Expressing jokes; Expressing wishes; Expressing gratitude; Giving clarification; Smiley emoticon; Giving compliment; Sharing similar interest;
Aug-14	1		II (Giving group information & reminding members to adhere to group's rules; Updating group photo;)						Expressing wishes; giving compliments; Seeking clarification; Expressing welcome & giving suggestions;
	2		III (Sharing social activities; Making announcement;	IIII III (Sharing social activity with other parents)	III	IIII	IIII IIIII	I (Sharing old post on group's rules)	Giving clarification & tagging others; Giving emotional support; Giving informational support & sharing links; Giving suggestions; Expressing gratitude;
	3		III (Seeking opinion; Welcoming new members & reminding the group rules;	IIII		IIII I	IIII II	I (links to products)	Giving suggestions & opinion; expressing welcome; Expressing humour; Expressing wishes; Sharing experiences; Giving clarification;
	4		IIII IIIII (Giving information; Making announcement & Tagging others; Giving suggestions; Giving information about AM FB; Sharing social story & Tagging others;	IIII IIIII (AM FB group's social activity-Eid)	I (location of event)	IIII II	IIII IIIII IIIII	I (Sharing old post on group's event)	Giving opinion; expressing welcome; Giving directions & clarification; Giving compliments; Smiley icon; Expressing humour; Tagging others; Seeking clarification;
Sep-14	1			IIII IIIII (AM FB group's social activity-Eid)		IIII I			
	2			IIII (AM FB group's social activity-Eid)		IIII IIIII	IIII		Expressing excitement; giving compliment; asking clarification & expressing gratitude; giving suggestion;
	3		IIII IIIII (Giving information; Making announcement; Giving suggestions; Giving information about AM FB			IIII II			
	4		III (Seeking opinion; Welcoming new members & reminding the group rules;			IIII III			Sharing experience & tagging name; giving emotional support;

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Jul-14	1	Participant 006				III	IIII		expressing disappointment, expressing anxiety & sharing similar experience, expressing wishes, expressing opinion,
	2		II (narrative of child's behaviour; expressing disappointment and hopes)			IIII	IIII II		expressing wishes, giving explanations, expressing gratitude, giving suggestions, sharing (similar) experiences.
	3					IIII	II		Asking clarification, informational support + name tagging, expressing gratitude,
	4		No activities conducted						
Aug-14	1		No activities conducted						
	2					II	I		expressing wishes,
	3		I (sharing experience of rewarding child)	I		III	I		expressing gratitude,
	4		I (narrative of child's social activity + expressing gratitude)	I		II	II		expressing anxiety + relief, sharing child's photo,
Sep-14	1					I	II		expressing wishes, expressing gratitude
	2		I (expressing disappointment)				III		Asking clarifications, expressing opinion,
	3		No activities conducted						
	4					II	I		expressing gratitude

Jul-14	1	Participant 007				I	I		Giving compliment;
	2		No activities conducted						
	3					I	III		Giving compliment & asking que; expressing gratitude & wishes; expressing wishes;
	4		I (expressing wishes & hope)				IIII		Asking que; asking opinion; tagging name & giving suggestion; asking que & sharing experience; expressing gratitude & wishes;
Aug-14	1		I (seeking informational support)			II	IIIIIIII		Expressing disappointment; sharing experience; giving compliment; expressing wishes;
	2						IIII		Expressing disappointment; expressing excitement; giving compliment
	3		I (expressing anxiety)			I	II		Expressing wishes; asking que & expressing gratitude;
	4		I (seeking info support)			I	II		Expressing excitement & disappointment; giving compliment; asking clarification & expressing gratitude;
Sep-14	1		No activities conducted						
	2						IIII		Sharing experience & expressing gratitude; asking que; giving compliment; expressing wishes
	3		I (expressing sadness)				I		Sharing experience ;
	4					I	IIII		Giving compliment; expressing wishes; expressing gratitude;

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Jul-14	1	Participant 008	IIII IIII II (sharing child's hobby & giving reminder to parents; expressing sadness & wishes; narrating child's achievement; sharing news obtained from TV; sharing movies related on ASD; expressing wishes; sharing child's conversation, sharing personal parenting skills;	IIII		IIII II	IIII IIII III	IIII (link on bean bags; online news; own blog;	giving clarifications; giving suggestions; giving encouragement; sharing other's experience & own experience; giving consent to participate in a study; expressing shock; expressing wishes; tagging other members; asking permission to share post; giving compliments; expressing gratitude; seeking clarification;
	2		IIII IIII I (sharing informational support; creating awareness; expressing gratitude; expressing anxiety for the future; expressing hope; seeking informational support; giving emotional support;	III		IIII IIII I	IIII IIII III	IIII (news portal; own blog for informational support & social activity;	Giving emotional support; expressing wishes; expressing sadness; giving informational support; expressing gratitude; giving suggestions; expressing anger; expressing happiness; expressing proud; giving clarifications;
	3		IIII III (sharing informational support; seeking informational support & expressing gratitude; expressing sadness; expressing wishes & gratitude; sharing/narrating child's social activity; expressing curiosity;		I	IIII IIII II	IIII III	IIII (own blog for informational support;	Giving clarifications; expressing proud; expressing gratitude; expressing disappointment;
	4		IIII IIII I (expressing wishes; sharing parents in AM FB social activities; sharing informational support; sharing child's social activities; expressing happiness;	IIII IIII III		IIII IIII	IIII IIII I	II (own blog;	Sharing own blog for informational support; expressing wishes; sharing similar experiences; giving compliments; giving suggestions; giving encouragement;
Aug-14	1		II (motivational quotes)	II		IIII	IIII	II (own blog)	Sharing own blog for informational support; expressing wishes; sharing similar experiences; giving compliments
	2		III (sharing informational support)	III		IIII II	IIII II	III (own blog)	expressing wishes; sharing similar experiences; giving compliments; giving suggestions; giving encouragement;
	3		III (sharing child's social activities; expressing gratitude)	III		IIII IIII III	IIII	III (own blog)	Giving emotional support; expressing wishes; expressing gratitude
	4		II (expressing sadness; sharing child's progress)	II		IIII II	IIII III	II (own blog)	Giving clarifications; expressing proud; expressing gratitude; expressing disappointment;
Sep-14	1		IIII IIII (motivational quotes; sharing experience on child's learning habit; child's school activity; child's funny moment; informing about TV show; narrating child's behaviour; expressing gratitude to child's teacher; informing of new ruling; wishing child's birthday;	IIII II		IIII IIII III	IIII IIII III	III (own blog; other FB page;	Giving suggestions; expressing prayer; Giving opinion; Giving compliments; giving clarification; sharing similar experience; expressing wishes; expressing gratitude; giving encouragement; tagging other member;
	2		IIII IIII I (giving motivation; sharing child's school activities; expressing gratitude; tagging others; expressing wishes; narrating child's achievement and expressing happiness;	IIII IIII II		IIII IIII III	IIII III	I	Expressing wishes; expressing jokes; expressing gratitude; sharing own blog for informational support; giving clarification; expressing anxiety; referring member to Files section in AM FB; giving suggestion;
	3		IIII (sharing child's school activities; expressing wishes; sharing child's social activity;	IIII		IIII	IIII IIII I	II (other's blog; own blog;	Giving compliments; expressing jokes; giving clarification; sharing similar experience and information; giving encouragement; expressing determination; expressing gratitude and giving awareness; expressing wishes; sharing similar experience; expressing disappointment over public's stigma;
	4		IIII IIII II (narrative on teaching own's child; additional learning kit; giving encouragement to own child; child's social activities; complementing other's child; informational support; narrating experience & giving suggestion; sharing prayers by children with ASD;	IIII II	III	IIII IIII III	IIII IIII III	III (own blog; Youtube learning video;	Giving clarification and expressing happiness; giving emotional support; tagging other members; sharing future plan & expressing gratitude; giving informational support; sharing youtube videos; giving compliments & encouragement; expressing jokes;

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Jul-14	1	Participant 009	I (narrating child's activity)	I		II	III		Giving clarification & expressing gratitude; giving compliments
	2		II (sharing conversation with child; narrating experience & feelings)	II		II	IIII		Giving clarification, expressing gratitude & tagging name; expressing regret & giving encouragement;
	3		I (sharing conversation with child & seeking emotional support)			II	IIII		Obtaining emotional support; expressing anxiety; expressing self-determination; feeling proud;
	4		II (sharing hobby; expressing disappointment & wishes;)	II		IIII	III	I	Expressing gratitude & giving clarification; sharing experience & expressing anxiety; sharing informational support;
Aug-14	1		II (sharing home therapy; sharing child's achievement;)	II		I	III		Giving clarification & expressing wishes; expressing sadness & regret; sharing similar experience & expressing gratitude;
	2		I (narrating unpleasant experience of social stigma;)	I		III	IIII		Expressing gratitude; seeking info support; expressing wishes; sharing experience;
	3		I (sharing narrative on emotional event with child)	I		III	IIIIII		Seeking emotional support; giving suggestion; giving emotional support; expressing happiness; giving clarification;
	4		I (sharing narrative on child's achievement at school)	I		II	IIII		Giving suggestion & encouragement; expressing gratitude; asking for suggestions; expressing self-determination;
Sep-14	1		I (expressing excitement of child's achievement at school)	I		II	IIIIIIII		Sharing similar experience; giving clarification; giving emotional support; expressing gratitude;
	2					III	IIII		Asking clarification & giving compliment; giving emotional support & making humour; expressing guilt;
	3					II	IIII		Giving compliment; asking for clarification & share experience; expressing gratitude & sense of belonging;
	4							II	Sharing experience, self-discovery & seeking support; expressing wishes & sadness; expressing hope; sharing similar experience & expressing guilt & regret; giving religious/moral support;

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Jul-14	1	Participant 010				II	III		Giving clarification; expressing determination;
	2		III (seeking info support)			III			
	3					I	III		Giving compliments; sharing experience; seeking informational support
	4		I (Seeking emotional support)			III			
Aug-14	1		No activities conducted						
	2		No activities conducted						
	3		III (seeking info support)			II			
	4		II (narrating child's behaviour & seeking emotional support)			I	III		Sharing experiences; sharing photo of child;
Sep-14	1		No activities conducted						
	2		I (expressing disappointment)			III			
	3						I		Expressing wishes; sharing link
	4		II (narrating child's behaviour & seeking emotional support)			II			

Jul-14	1	Participant 011	I (sharing link on home therapy)			II	III	I	tagging name; giving suggestions;
	2						IIII		Giving compliments; sharing experience; informational support
	3		I (sharing child's work)	I		III	IIII		Expressing wishes; expressing gratitude; asking que; giving clarification;
	4		I (sharing child's work)	I		IIII	III		Giving clarification; expressing determination; sharing link;
Aug-14	1						II		Survey completed; giving assurance;
	2						II	I	Giving clarification; informational support- sharing link;
	3					II	II		tagging name; giving clarification;
	4		I (sharing article's link)	II		II	II	I	tagging name
Sep-14	1						II		Expressing gratitude & wishes & tagging name; giving clarification;
	2					III	II		Expressing wishes; tagging name
	3					IIII	II		Expressing wishes; sharing link
	4			I		II	III		Sharing experiences; sharing photo of child;

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Jul-14	1	Participant 012	III (seeking info support)			II			
	2		II (expressing sadness; sharing child's progress)			III	III		Giving compliments; sharing experience; informational support
	3		No activities conducted						
	4		No activities conducted						
Aug-14	1		I (narrating unpleasant experience of social stigma;			II	II		Expressing gratitude & wishes & tagging name; giving clarification;
	2		II (seeking info support)			I	II		Expressing wishes; tagging name
	3		I (narrating child's behaviour & seeking emotional support)			I	II		Expressing wishes; sharing link
	4		No activities conducted						
Sep-14	1		I (expressing disappointment)			II	III		Asking clarifications, expressing opinion,
	2		III (seeking info support)						
	3					III	III		Sharing experiences; sharing photo of child;
	4		I (narrating unpleasant experience of social stigma;			III			



## Appendix 7: A sample of archived Facebook data



**Appendix 8: A sample of interview transcript**

***Could you share some brief information about yourself and your child?***

Okay, my name is Zamri Tembol. My son is Hariz bin Zamri..err..he was diagnosed of having ASD at the age of 3, err..in 2004 lah. Lahir 2001, so 3 thn..2004 lah. So, dia ada autism plus ADHD. So, dia ada kesemua ciri2 autism pd ms tu. Jd..err..stlh apa tu..err..stlh berusaha utk mendapatkn rawatan, sokongan dan so on..err..di mana di Malaysia ni susah nk dpt..err..apa tu, info..information..err..sokongan. Jd pd tahun 2010 tu..err..sy membuat keputusan utk mem..membuat satu group Autisme Malaysia..err..dan..dan dimulai dgn, kalau x silap sy hanya 4 ke 5 family sahaja pd ms itu yg direct ada anak autism. Itulah sehingga skrg.

***Could you share the whole experience in using Autisme Malaysia Facebook support group?***

Ok, sy sharing sbb sy yg create group AM tu. Apa yg motivate sy create AM tu, satu..information x cukup, yg keduanya sy perlukan reference drpd..apa tu..parents2 yg pernah melaluinya sbb sy yakin ada parents yg dh melaluinya cuma kita x tahu. And then dkt hospital, mcm Marina ckp td, dia kata..apa tu..sokongan di hospital2 ada cuma sebulan sekali atau 2 minggu sekali tp dibuat waktu bekerja. So, kita yg dibuat waktu bekerja ni, susah lah kan. And then bila kita attend that sharing, it's more on one-way talk instead of two-way talk, still x cukuplah bg sy pd ms tu. And then bila..err..berdasarkn pd skill yg sy ada, sy google, tanya cikgu Yaakob apa semua, bila taip 'autism' semua merujuk pegi ke UK, pegi ke Japan, pegi ke US..x de ke M'sia. That's why sy just x pe lah, kita create saja Autisme Malaysia ni, mana tau satu hari nanti dia berguna. Itulah..dkt situlah sy mula post all the activities yg anak sy ceritakn, ups and downs dia, ups and downs kita pun kita cerita. So, it's kind of a place utk kita relieve kn kita punya stress, bebanan sedikit kpd yg memahami supaya kita boleh go on dgn llife. Disamping tu, tujuannya utk create awareness lah.

***If you were to upload a status, what kind of responses did you receive? How do you feel about it?***

Err..pengalaman posting, so..err..sy main dua peranan lah, satu peranan admin dan satu peranan parents yg ada anak autistic. So sy pd awalnya kalau sy boleh recall, posting2 sy agak negative jugalah sbb berdasarkn pengalaman yg sy lalui utk beberapa tahun awal tu dgn sek nya, dgn masalahnya, mcm2..so more on a place to throw all the anger n everything. So after a certain stage, a certain period n I realised that one is a waste of my energy, so I peace my mind to post all the

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positive things. So, I changed that. So Alhamdulillah I success to change the role. So mmg ada yg lps posting2 sy mmg sy akui ada posting negative n posting positif. Posting negative tu slalunya akan mengundang all the controversial which is sekali org komen akan smpai beratus2 lps tu ada smpai nk bergaduh pun ada. Cthnya isu on vaccination, 'cause ada yg pro vaksin, ada yg totally opposite side, kn. Jd kita main peranan di tgh2 lah, disamping parents, kita main peranan di tgh2. Kita tidak mahu ada parents yg extreme..to the extreme sbb autism x de rawatan atau penyebab yang..yang pakar boleh kata definite, this is the reason. So x de lg. So, kita kena highlight yg tu selalu. Jd..err..action yg kita buat adalah kita letakkn notes2, info2 yg kita dh collect apa benda sbg summary so bila ada isu aje, kita akan shoot this notes. Bila ada isu, kita akan shoot this note so sedikit sebanyak ia meredakn controversial tu lah and all these pro-vaksin atau bkn pro-vaksin punya org ni, dia..dia hormat, pay respect to all this group punya policy lah. Alhamdulillah lah.

And sometime Zamri terpaksa mention jika post ni berlanjutan dia punya komen2, komen2 dh terlalu ni (hangat) , post ni akan di delete, truslah baru diaorg reda (chuckles). Bincang secara normal lah.

So, bila ada nmpak..sy akn go through all the postings, go through at glance n bila nmpak certain things akan trigger, kita tau lah apa outcomes dia, so kita akn tgk sama ada benda tu berlanjutan ataupun stop. Kalau stop, baru kita delete dn kalau berlanjutan, kita akan cut. So mcm tu lah sy..kita punya ni (duty).

### ***So, how often do you play the role as admin?***

Everyday..everyday mmg kena tgk. Kdg2 bila x de masa, mcm admin2 lain akan tlg..minta tlg sbb kita ada..dulu sy sorang2 ms awal2 tu n after certain stage, kita appoint a few people sbb sy fikir..err..sy sorang x boleh nk manage semua kn. So, kita form a group so this group yg..yg monitor jgk lah. So sy jg akan tgk mana yg too negative, then kita trus potong lah. Tu cara kita manage tu.

### ***How did you respond to other people postings? Did you look at the content of the status or the person posting the status?***

Biasanya sy akan go through, nk respond sy akan go through..kalau perlul respond, sy respond. Tgk comment jgk, kalau dh ada..sy x respond. Kalau mcm x de, kita respond and then ada certain yg kita x mahir tp kita tahu ada org yg mahir, kita tag dia..kita tag nama dia so org akan explain, chip in.

So, mcm tulah. Err..slalu jgk nmpk org tag admin. Haa..so maknanya dia mintk kita respond lah. So bila ada mcm tu, kita kena respond jgk lah sbb org dh tag kita kn.

***Ok, what about the Like button? Do you think the Like is important when you post a status or do you think it's important for others?***

Err..sy secara peribadi, sy x..sy x tgk Like tu. Sy lbh prefer tgk comments, response to what I have written there tp sy Like org punya (laugh). So what's d reason u..? Sy suka Like org punya sbb utk menyokong dia supaya dia terus posting things. So, maknanya u Like based on content ke..? Content..based on content. Err..sy dh sampai ke satu tahap yg lbh pd parents2 yg ada anak 2 org special, 3 org special which is sy suka bila sy jumpa tu, sy try visit diaorg. Pd sy..err..bila sy tgk diaorg actual nya, sy jd..jd lbh bagus lah, maksudnya "dia tu 3 org, aku baru sorang, apa lah sgt". So something yg mcm gitu lah. Jd sy mencari yg ke arah lbh mcm tu lah dan pd ms yg sama, realitinya bila sy pergi actual mcm tu, nobody visit them actually. So, it's a..org kata tu, sy..sy menjadi lbh kuat lah kot utk..utk sustain kn group ni. Sy..sy mcm parents punya perspective punya post tu, sy akan buat mcm post yg trigger parents utk berfikir instead of..instead of kita sekadar berkongsi shj. So bila kita post something, kita drive dia utk think..kenapa kita buat mcm tu. Haa..so byk nya mcm tu la sy punya respond. Cthnya? Cthnya mcm..err..apa tu, anak sy dia stick pd rutin kn, so certain thing mcm dulu dia suka mkn nasi lemak mesti bukak PSP, mkn je bukak PSP. Sy x cerita benda tu sehingga sy..sehingga sy jumpa dia punya solution tu kn..dia punya solution tu. Sy cerita bila solution tu dh berjaya, so sy cerita..sy cerita . bila org tanya kn, actually proses tu mengambil masa berbulan2 utk kita. So kt situ sy twist diaorg punya mind..err..the solution does not come in short, so dia mkn masa..so mcm tu lah. Kecuali ada yg tiba2 kn, eh dia buat mcm ni lah tp kita x buat apa2..so sy akan trus share lah, maknanya it's unexpected kn. Tp utk yg..yg kita dh expected kn, slalunya kita akan post at the end dia punya result. So bila ada result, sy akan story balik. Sy akn put somewhere cerita tu dn sy post kt situ.

***Is there anything you would like to change about this group or something that you think needs to be sustained?***

Bg sy, yg perlu di kekalkn tu..setuju yg positive vibes tu di kekalkn dn negative vibes tu dikurangkn. Kalau boleh, dijauhkan lah. Then apa tu..sy ingin melihat AM members walaupun dia x join persatuan sbg official members, they have..err..dlm fikiran, apa2 yg diaorg buat dn tindakan tu

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adalah utk mengubah masa depan komuniti autism, it's not their own family or their own son,child only. Itulah harapan sy dn diaorg boleh pergi to that direction otherwise skrg kita lihat soalan2 ni, soalan2 yg sama akan ada pd 10 tahun akan dtg kalau parents x de that kind of thinking. So, itulah harapan sy.

**Appendix 9: Free/Open codes**

Free nodes OR open coding			
Name	Sources	References	
urge or motivation to take action	10	41	
Understanding	9	36	
transition	3	4	
theory plus practise	2	3	
Teachers' role	5	12	
subtle way of advising	1	2	
Story telling & characterisation	1	1	
social support in general	7	19	
Social Stigma	8	39	
showing care	6	16	
showing appreciation	3	8	
Sharing tips or info	6	11	
sharing as a way to communicate	4	5	
self-realization	13	69	
Selfless	9	30	
Self value	4	9	
self rewarding	1	1	
Self discovery	5	19	
self determination	5	14	
Sacrifices made	8	15	
restructuring life	2	4	
Resources available in AM FB	3	3	
reserving comments	3	4	
quotes and sayings	4	5	
Putting knowledge into practise	1	1	
purpose of postings	9	29	
prayers & religious support	8	18	
positive improvement	7	8	
personal experience	5	6	
offering help and advice	10	52	
offering encouragement	14	51	
obstructed freedom of expression	1	1	
Obligation	7	17	

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Free nodes OR open coding			
Name	Sources	References	
Noticing	4	7	
No knowledge	6	16	
Networking	8	42	
Narratives	1	1	
Motivation to join AM FB	4	6	
low self-esteem	2	5	
'Like' function	7	14	
Language use	2	2	
informational support	15	63	
Impact of AM FB	0	0	
How they found AM	4	4	
Hope for AM FB	5	9	
given up hope	4	4	
gender issue	1	1	
From private to public	2	2	
First reaction	3	4	
Feeling lost	4	4	
expressing shock	5	8	
expressing sadness	7	17	
expressing regret	5	13	
expressing loneliness	3	3	
expressing gratitude	12	89	
expressing excitement or happiness	9	41	
expressing disappointment	7	21	
expressing astonishment	8	14	
Expressing anger	6	7	
Experiences gained	3	6	
engagement in AM FB	3	4	
emphatic support	3	4	
Emotional support	11	50	
Emotional stress	13	38	
Doctor's limited knowledge	3	4	
Denial state or self denial	4	11	

Free nodes OR open coding			
Name	Sources	References	
creating tense or controversies	5	13	
creating awareness	9	19	
Constraints faced by parents of ASD Malaysia	2	2	
Challenges of parenting	7	23	
Challenges of AM FB	7	21	
being selective	1	1	
Being humble	1	1	
becomes strong emotionally	1	1	
Becomes knowledgeable	7	18	
as motivating factor to others	3	4	
Admin responsibilities	6	13	

## Appendix 10: Axial Codes

**Nodes**

- Free nodes OR open coding
- Secondary level nodes OR axial coding
  - Challenges faced by ASD parents
  - developing positive attributes
  - freedom of expression
  - Hope and expectation
  - Impact of AM FB
  - Parents early reactions
  - Self-driven motivation
  - Social responsibilities practices
  - Social support
  - Things shared on AM FB
- Third level coding or Categories
- Cases
- Relationships
- Node Matrices

**Sources**

**Nodes**

**Classifications**

**Collections**

**Queries**

**Reports**

**Maps**

Look for  Search in  Challenges face Find Now Clear Advanced Find

**Challenges faced by ASD parents**

Name	Sources	References
Challenges of AM FB	7	21
challenges of education	3	5
Challenges of parenting	6	21
Constraints faced by parents of ASD Malaysia	2	2
given up hope	1	1
introvert	2	5
No knowledge	6	16
Social Stigma	6	30

**Social Stigma**

[\[Internal\Interview\\_data\Central region\2015.02.04\\_05.29 P001> - \\$ 2 references coded \[6.35% Coverage\]](#)

**Reference 1 - 3.27% Coverage**

Sometimes benda yg kecik diaorg share ttg progress anak diaorg, it's actually pd kita, it's very good. it's very big pd kita kn. So, kita nk bg encouragement pd dia. Okay, x pe. benda ni pd org luar mungkin nmpk kecil, pd kita..hey that's good enough! X pe, kita Like that post kn.

**Reference 2 - 3.08% Coverage**

Kdg parents mcm nil ah, mcm kita yg ada anak mcm ni kn..benda tu sikit je tp kita nk share dgn org yg faham. Sbb kalau kita share dkt wall kita sendiri pun kn, kun2 kita yg mmg x tau, yg x sekuat dg kita ni.. "eleh, benda mcm ni pun nk cerita". Diaorg x faham tau

[\[Internal\Interview\\_data\Central region\2015.02.04\\_05.29 P004> - \\$ 1 reference coded \[0.80% Coverage\]](#)

**Reference 1 - 0.80% Coverage**

Sbb autism ni..dia bkn fizikal disability, dia hidden. So family sendiri pun susah nk faham.

[\[Internal\Interview\\_data\Central region\Transcription\\_central\\_P002> - \\$ 8 references coded \[4.53% Coverage\]](#)

**Reference 1 - 0.96% Coverage**

So, I was asking to start work at 9am n finish at 9pm. So, both of my boss agreed n I was relieved. Tr distance from Cyberjaya to UKM is farther than Cyberjaya to Putrajaya. So I tebakn muka request for my break time to be one n half hours so that I can commute.

**Reference 2 - 0.72% Coverage**

Sy rs devastated bila sy tau suara2 sumbang yg bertanya kenapa kita dpt special treatment mcm tu sdgkn sy rs physically lethi, bangun awal, htr anak, drive laju2, kdg2 x mkn lunch..so ada yg complai

**Reference 3 - 0.43% Coverage**



## Appendix 11: Categories based on axial codes

The screenshot displays a qualitative data analysis software interface. On the left, a hierarchical tree of nodes is shown, with 'freedom of expression' highlighted. The top of the interface features a search bar with the text 'freedom of expr' and buttons for 'Find Now' and 'Clear'. The main area is divided into two sections: a table of results for 'freedom of expression' and a detailed view of a selected reference.

Name	Sources	References
Emotional stress	8	25
Expressing anger	3	3
expressing astonishment	3	3
expressing disappointment	1	4
expressing excitement or happiness	2	5
expressing feelings	3	5
expressing gratitude	5	13
expressing shock	1	1
Feeling lost	2	2
freedom of expression	2	3
From private to public	2	2

The detailed view on the right shows a selected reference with the following text:

**Reference 1 - 5.95% Coverage**

Kdg apa yg kita rs benda tu positive, org yg baca tu sbb benda yg di post dlm FB ni dia x de nada..jd org mudah utk misinterpret apa yg kita tulis. Sometimes ada org yg berkecil hati dgn posting kita dan ada yg salah faham. So, emosi tu lah yg nak..yg paling susah sekali nk tackle kalau melalui FB ni. Itu je sy nmpak cabarannya sbb org yg komen, komen negative tu pun..dia bertindak berdasarkan apa yg dia baca tanpa memahaminya, yg kita menerima pun kdg2 nk respon, kalau x gunakan hikmah mmg jd emosi jgk lah.

**Reference 2 - 2.37% Coverage**

Kalau dh smpai teruk sgt, we have to delete the posting because x nk create tension dlm tu kn. Jd bila baca pun, org yg x de kena mengena..baca komen tu pun boleh jd menyirap, jd negative vibe k situ kn.

**Reference 1 - 4.78% Coverage**

I joined Autism Malaysia (AM) in 2012. At that time, I logged in every day, I updated status every day because it's more of sharing my feelings to others. Before I joined AM, I used to share in my own wall but not many people understand, they would ask. Then when I found AM, sharing with people who are similar as you like Zamri, parents who are in the same shoes... it was a really big relief!

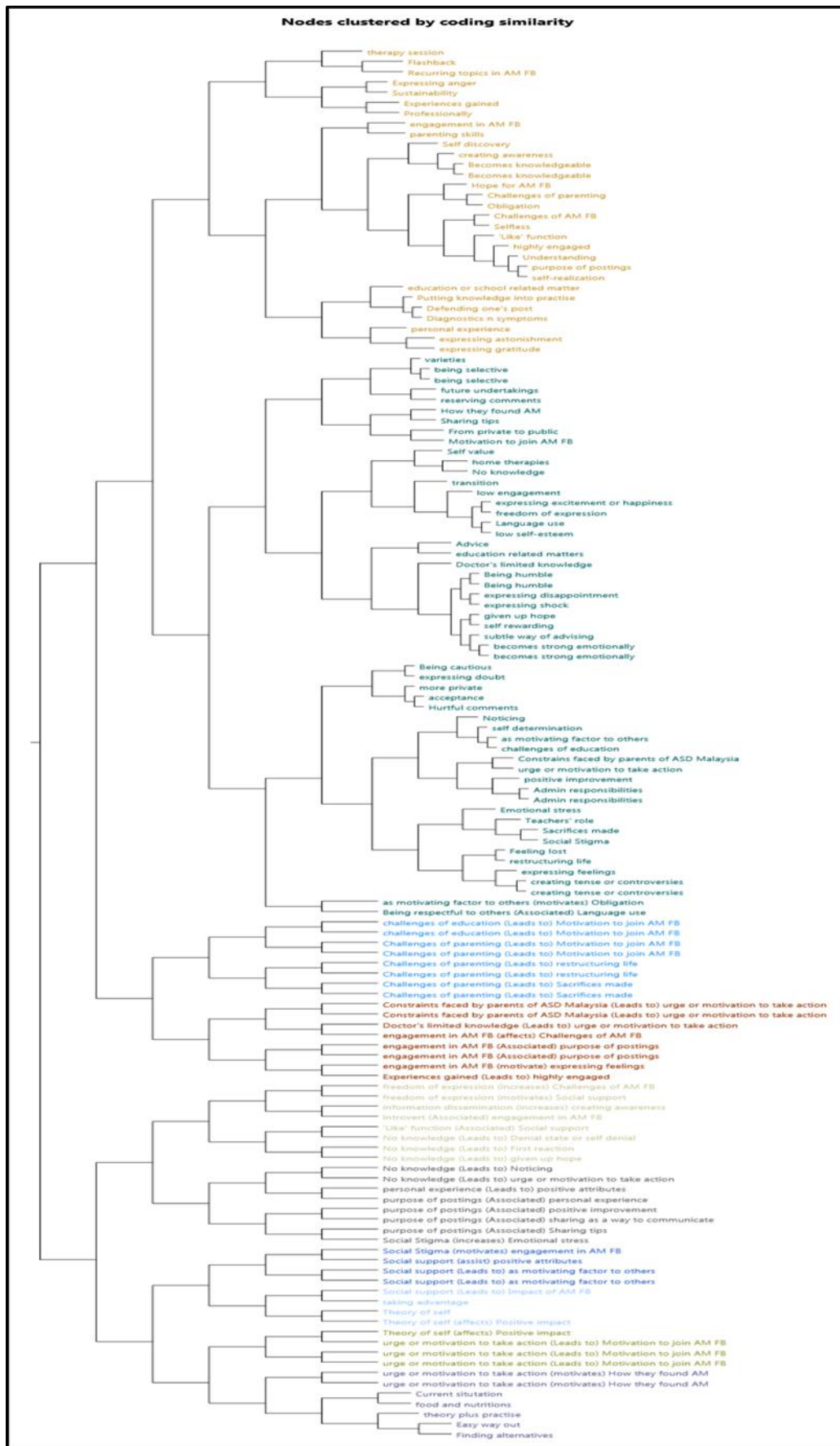
**Reference 2 - 1.19% Coverage**

They fail to understand that autism is not an illness. So when that happens, they become frustrated.

**Reference 1 - 5.98% Coverage**

**Reference 1 - 4.23% Coverage**

## Appendix 12: Nodes clustered by coding similarities and relationships



**Appendix 13: A sample of relationships between codes**

